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Vaccine information-seeking behaviour: its predictors and influence on vaccination during pregnancy

Richard Matthew Clarke

**Thesis submitted in accordance with the requirements for the degree of Doctor of Philosophy of
the University of London**

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Department of Infectious Disease Epidemiology

Faculty of Epidemiology and Population Health

London School of Hygiene & Tropical Medicine

Funded by the Economic and Social Research Council

Research group affiliation: The Vaccine Confidence Project

Primary supervisor: Dr. Pauline Paterson
Assistant Professor
Department of Infectious Disease Epidemiology
London School of Hygiene and Tropical Medicine

Co-supervisor: Dr. Miroslav Sirota
Senior Lecturer
Department of Psychology
University of Essex

Advisory Committee members: Helen Campbell
Senior Clinical Scientist
Public Health England

Dr John Cairns
Professor of Health Economics
London school of Hygiene & Tropical Medicine

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Thank you all!

Declaration

I, Richard M Clarke, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

I have read and understood the School's definition of plagiarism and cheating given in the Research Degrees Handbook. I have acknowledged all results and quotations from the published or unpublished work of other people.

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Date:

Full name: Richard Matthew Clarke

Abstract

Pregnancy represents a high information need state, where uncertainty around medical intervention is common. As such, women often engage in vaccine information-seeking behaviour, a process that involves the gathering and use of information to inform the vaccine decision-making process. If this seeking occurs outside of official healthcare system channels, many healthcare professionals are concerned that this behaviour may lead women towards less reliable, potentially misleading information. The concept of vaccine information-seeking during pregnancy therefore warrants examination.

In this thesis, I present two systematic reviews and two quantitative research papers related to the topic of vaccine information-seeking behaviour. These studies investigate the predictors of and influences on vaccine information-seeking behaviour both in general and specifically relating to UK women making a decision regarding the pertussis vaccination for pregnant women. In the systematic reviews, I synthesise the literature related to the measurement of trust in vaccination and how vaccine information-seeking behaviour has previously been investigated throughout the vaccine attitude and decision-making literature. The literature from these two review papers informed the design of two quantitative questionnaire studies. The first of these investigates the determinants of satisfaction with official information and the additional information-seeking behaviour of recently pregnant women in regards to the pertussis vaccination given during pregnancy. The second investigates how previously held attitudes towards vaccination influence vaccine information-seeking behaviour, and how such behaviours may in turn influence the vaccine decision-making process.

Findings from the first quantitative study indicate that a higher trust in one's healthcare professional, a perceived ability to seek out accurate information about vaccines, and actively engaging with problems as a means of coping with stress, predicts satisfaction in the official vaccine information. While a large minority (approximately 40%) of women searched for

additional information about the pregnancy pertussis vaccine during their pregnancy, neither satisfaction related to official information, nor attitudes towards vaccination, predicted vaccine information-seeking behaviour.

From my second quantitative study, the length of time that individuals spend seeking information was associated with a higher perceived risk of pertussis disease and a lower confidence in vaccination. Intention to vaccinate was found to relate to the perceived influence of such found information, with higher intention to vaccinate being associated with respondents reporting that the information they found pointed them towards vaccination and lower levels of intention to vaccinate being associated with respondents reporting that the information they found pointed them away from vaccination. When I examined attitudes across the course of a pregnancy, a significant shift in risk perception occurred whereby women became more risk averse to the disease of pertussis as compared to the vaccine that protects against pertussis. This shift was not found to be associated with vaccine information-seeking behaviour, strength of vaccine recommendation for respondent's healthcare professional or vaccine uptake.

This line of research demonstrates the role of vaccine information-seeking behaviour within the vaccine decision making process. Information related to the pertussis during pregnancy vaccination is rarely judged on its own intrinsic qualities instead it is viewed through a range of pre-existing beliefs and social contexts. With midwives being the health care professional that conducts the majority of the vaccine communication in regards to this particular programme, it is vital that midwives are given the time and available resources to build strong relationships with their patients and feel that they have the self-efficacy to effectively communicate vaccine information. This would undoubtedly be of benefit to the pertussis during pregnancy vaccination programme, but would also better guide women towards reliable information sources in regards to subsequent childhood vaccinations.

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“...we did not anticipate that people would decide not to be vaccinated... In today’s world, people can draw on a vast range of information sources. People make their own decisions about what information to trust, and base their actions on those decisions. The days when health officials could issue advice, based on the very best medical and scientific data, and expect populations to comply, may be fading.” Dr Margaret Chan, World Health Organisation

Director General, in reference to the H1N1 vaccination in 2010 (1)

1. Introduction

Ever since the ubiquitous introduction of vaccination as a public health intervention, there has been a small minority of those within society who have firmly opposed the process (2,3).

Reasons cited for this opposition are numerous (3), however, these reasons can often be found to relate to the concept of scepticism, either in the product and procedure of vaccination or in the trustworthiness of the systems or individuals that provide them (3–5).

Scepticism, in and of itself, is not necessarily detrimental to the desired public health outcome of vaccination, in fact scepticism forms the very concept on which the scientific method is built (6). Scepticism, however, becomes problematic when it is employed improperly and to the level that reliable scientific and public health concepts are subjected to unskilled questioning in a way that undermines and misrepresents the principals they are founded on (7–9).

Historically, the dissemination of information unduly critical of vaccination has originated from fringe social and political movements (2,10), either established by parents with concerns that a vaccine has injured their child or by individuals who hold a high level of distrust in governmental intervention in general (11). Occasionally, vaccine criticism has been communicated through the more publicly accessible means of the mainstream print and broadcast media (5,12,13). When done so this has been seen to spark widespread public debate on the topic of vaccination (14).

Since the advent of the internet, the public's relationship to vaccine information has changed dramatically. The internet facilitates a departure from relying on healthcare professionals or broadcast media for information about vaccination and instead empowers users with immediate, easy access to a wide range of health information sources of variable quality (15–17).

In 2002, it was estimated that approximately 43% of search results for the term “vaccination” led to websites critical of vaccination (18). A typical website that is critical of vaccination covers themes such as alleged collusion between doctors and the pharmaceutical industry, an over-emphasis and misattribution of vaccine side effects (often accompanied by an emotive narrative), and understated dangers of vaccine preventable diseases (19).

In the mid 2000’s another information-related shift occurred due to the advent of the so-called “Web 2.0” and the proliferation of social media platforms such as Facebook, Twitter and YouTube. With this change, not only could users seek vaccine information through the additional search engines on these platforms, they could become the creators, curators and disseminators of their own vaccine information. The extent of publicly accessible vaccine critical information on social media platforms has been well documented (20–28). Together with an accessible interface and the ease with which information can flow through personal networks it is understandable why some have referred to vaccine information on social media as a postmodern Pandora’s Box (29) and as such suggest that we are now living in the golden age of anti-vaccine conspiracies (30).

The focus on the content existing on these platforms, however, often disregards a key factor in vaccine hesitancy and refusal: the role of the individual actively engaging in the information gathering and synthesis process. In this thesis, such a role is examined in order to benefit our understanding of the use of information within the vaccine decision-making process, how information-seeking interacts with vaccine related beliefs and how this in turn may lead to an individual refusing or delaying a vaccination that has been scientifically certified as a safe and effective medical intervention.

1.1 Health information acquisition

When faced with a health decision or medical diagnosis an individual may engage in a form of seeking behaviour to gather additional information. With the recent shift in many high-

income countries to a shared-decision making model of healthcare, doctors and patients both frequently engage in seeking information to diagnose and treat illness (31), with patients providing information on their previous health status, values and preferences, and the healthcare professional providing medical options and risk information. This cooperative patient centred model of healthcare has coincided with the rise of health information acquisition as an area of academic inquiry. Broadly speaking health information acquisition includes the concept of health information-seeking behaviour and health information scanning (32–34).

Health information-seeking behaviour involves the verbal and non-verbal behaviours used to attain, clarify or confirm information (32); often this process requires a perceived need for information (35). Once a need for information is present, the activation of the behaviour can be due to a lack of satisfaction with levels of held information (36), a need to reduce the accompanying stress (37,38), and/or general curiosity and the desire to be informed (39).

Three information specific factors are involved in the seeking and subsequent acquisition of health information: these are the *message*, *source* and *channel* of communication (33).

Messages being information imbued with meaning (often including a behavioural recommendation), *sources* being an organisational body or specific person that communicates a message (e.g. the NHS, Natural News, the US government) and *channels* being the method by which a source communicates its messages (e.g. TV, the internet, newspapers).

Sources can communicate through a number of different *channels*, for example, the NHS may communicate a message in person through a GP, through the internet and through the TV news. *Messages* may stay relatively consistent within *sources* (e.g. the NHS pro-vaccination messaging related to the HPV vaccine) or may be subject to change over time (e.g. introduction to a new vaccine or a change in the vaccine target group).

When information-seeking behaviour is performed, Johnson and Case (33) suggest that such a behaviour exists within the confines of an individual's own personal arrangement of preferred channels and sources known as their *information field*. An individual's beliefs, attitudes and intentions influence the choice of *channels* and the selection of *sources* that an individual may use for information (40); as such an individuals' *information field* can be subject to change as an individual interacts with sources throughout the course of their life.

Information acquisition from the *information field*, however, does not necessarily require an active behavioural process. Information scanning, sometimes referred to as everyday-life information seeking, is the routine exposure to or "discovery" of information through passive means or through the monitoring for a specific topic (34,38,41). Often neglected in information acquisition research, perhaps due to its difficulty to measure, this incidental form of information gathering is potentially an equally important guiding force in health belief formation and decision-making (34).

1.2 Health information and trust

Across this thesis, the concept of trust is examined as it relates to risk management (42). The definition I have adopted for trust is from Rousseau *et al* (43) and is as follows:

"...a psychological state comprising the intention to accept vulnerability based upon positive expectations of the intentions or behaviour of another" (43) p. 395.

To this end, the TCC model of Trust, Confidence and Cooperation (44,45) is my main theoretical model of choice for examining the concept. The model consists of two dimensions that together summate to the above definition of trust. The first is the concept of *confidence*, the perceived performance or competency aspect of trust, and the second is the concept of *social trust*, the perceived morality or shared values aspect of trust. When these two concepts are combined according to the model (see figure 1), *social trust* has an additional mediating effect on *confidence*. For instance, trust is more likely to be lost in a competent healthcare

professional if they are perceived to value financial incentives from a pharmaceutical company above the health of a child, a violation of *social trust*, as compared to a similar healthcare professional who makes a diagnostic mistake, a violation of *confidence*, while being perceived as having their “heart in the right place”.

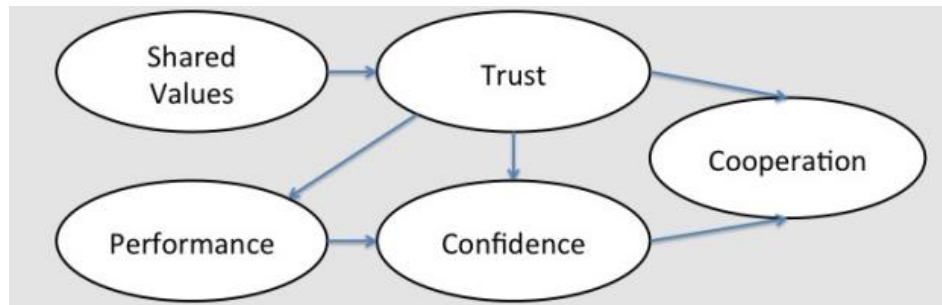


Figure 1: Simplified TCC Model of Trust, Confidence and Cooperation (45). Image reproduced with permission of author (See Appendix A).

Other models, such as those suggested by Anderson and Dedrick (137), Hall et al (76) and Meredith et al (269) include a broader definitions of trust by including additional concepts such as honesty, in which perceived holding back knowledge or only “telling half of the story” is taken into account, consistency, in which trustworthiness over time is key, and confidentiality, a concept that includes perceived ability with sensitive information. These models also include concepts that overlap with shared values the shared values concept of the TCC model such as fiduciary responsibility and fidelity.

In Chapter 2 of this thesis I examine the measurement of this definition of trust as it pertains to vaccination. In this systematic review, I review 35 articles that investigated the perception and uptake of vaccines where the author’s primary research question focused on the concept of trust. Aspects related to the definition and measurement of trust were extracted and recommendations are made as to the investigation of the concept in future vaccine hesitancy research.

1.3 Vaccine information acquisition

The seeking of, and passive exposure to, additional vaccine information is common during the vaccine decision-making process, and is unique to each individual and for each vaccination. This quote from Boyd and Gazmararian (46), in which the authors interviewed women about their vaccine decision making during the H1N1 pandemic, exemplifies the complexities of the vaccine information acquisition process:

“Initially, the participants expressed concern and fascination with media coverage of the outbreak. This sparked questions and conversation. After consulting friends and family, several women went online to seek information. Yet, these women described frustration over their ability to find accurate information. Eventually, the women shared a mutual exhaustion over what they perceived to be the oversaturation of messages inducing fear. As a result, many adopted an attitude of avoidance.” Boyd and Gazmararian 2013, p.857 (46)

The seeking behaviour described here is similar to Wheelock *et al*’s notion of a ‘*Journey to vaccination*’ (47), in which information gained from various sources, over time, plays a key role in continuing to shape an individual’s perception of, and intention towards, vaccination. Within this process, vaccine information acquisition can be seen to fulfil a number of important roles, from diminishing uncertainty (48), to aiding social acceptance (14), to coping with decision stress (49).

During vaccine related health scares such as the extensive news coverage surrounding the (now thoroughly debunked) claims surrounding the MMR vaccine, or the threat from the 2009/10 H1N1 influenza pandemic, parents’ information needs increase and become more immediate (50). Furthermore, during pregnancy, and more so with problem pregnancies, health information needs are said to frequently go above what the official literature is able to provide (51) and may form a vital role in the preparation for parenthood (52).

In my second systematic review (chapter 3), I examine vaccine information-seeking behaviour and vaccine information scanning across 52 peer reviewed articles. In the review the prevalence of, and antecedents to, vaccine information-seeking behaviour are examined and summarised across a range of vaccines. In relation to these findings, *channel* and *source* selection are summarised, and the effect of vaccine information-seeking and scanning on vaccine attitude, intention and uptake is assessed.

1.4 Pertussis vaccination during pregnancy

In Chapters 4 & 5 I report two quantitative studies in which I investigate the vaccination information-seeking beliefs and behaviours of women in regards to the pertussis vaccination currently recommended to all pregnant women as part of the standard vaccination schedule in the UK.

The vaccination of pregnant women against pertussis (also known as whooping cough) has been recommended in the UK since approval from the Joint Committee on Vaccination and Immunisation (JCVI) was granted in September 2012 (53). Initially introduced as a reaction to a sizeable outbreak of the disease that led to the deaths of 14 infants in early 2012, this temporary vaccine recommendation was subsequently extended (54) and is now standard practice for the foreseeable future. Prior to this vaccination programme, immunity from pertussis, across the UK, was achieved through regular childhood vaccination using the 5 in 1 tdap vaccination, however, even with a high coverage rate in children (>95%) the 2012 outbreak of the disease still occurred (54). Safety and efficacy research (55–57) suggests that the addition of the same vaccine during pregnancy was justified and consequently mothers between 16 and 36 weeks of pregnancy are now currently recommended the vaccine. Vaccination, during this time period, offers mothers protection from pertussis whilst passing on temporary protection to their baby until they are old enough to receive the regularly scheduled childhood version of the vaccine (58).

A large (N=1892), nationally representative, survey conducted in January of 2013 explored attitudes towards the pertussis during pregnancy vaccine in England and Wales shortly after its introduction. The survey indicated a strong willingness to vaccinate, with 94% of respondents indicating that they ‘definitely’ or ‘probably would’ accept a vaccine during pregnancy offered by their GP or midwife (59). With uptake since introduction varying from approximately 50% to 70% (54), a sizeable disconnect between intention to vaccinate and uptake has existed. While this disconnect is common in vaccine attitude and uptake research, and may link the high level of caution women show towards medications given during pregnancy (60), there is a likelihood that some of this uptake deficit may be due to situational issues involved in the initial delivering the vaccine. For instance, the lack of patient group directions (PGDs) in place early in the programme meant that midwives could not offer the vaccine directly, and instead women would have to make an additional appointment with their GP to receive the vaccine, increasing the amount of effort involved to vaccinate. Since this was corrected, further issues of midwives lacking the self-efficacy to give advice about the relatively new vaccination procedure (61) and as such not giving as strong a recommendation, may have formed a key factor in low vaccine uptake (62–64).

A related factor to recommendation is the communication of vaccine related information within consultations. A 2015 London focused survey of pregnant women proposed information needs as a significant barrier to uptake of the pertussis vaccine (65). Uptake of the pertussis vaccine during pregnancy was low in this study with only 26% of women vaccinating during their pregnancies. Of the women who had not vaccinated during their pregnancy 51.3% indicated that they were not aware of the vaccination program and 32.6% cited that they did not vaccinate due to a lack of information to make the decision (65). Furthermore, the vast majority (91%) of all women in the study believed that their healthcare professional should have provided additional, detailed information about vaccination during

pregnancy (65). The previously mentioned study from 2013 (59) also examined information needs of the women who were offered the pertussis vaccine. Of these women 69.7% reported that they had received enough information for them to make their decision while 21.3% felt they had some but would have wanted more, and 8.9% either had none or not enough. These findings point towards a perceived information deficit in approximately a quarter of individuals making their decisions to vaccinate for pertussis during pregnancy.

While the pertussis vaccination programme in pregnancy has undoubtedly become more established since its introduction, the process of vaccinating this particular population presented a unique landscape for investigating vaccine decision-making and information-seeking behaviour, different from that of the standard childhood and other adult vaccinations.

1.5 Aims of the following chapters

This thesis includes four research papers that examine different aspects of the vaccine decision-making process in regards to vaccine information-seeking behaviour. The papers that form chapters 2 & 4 have been published in the journals *Human Vaccines & Immunotherapeutics* and *Vaccine* respectively, while the paper that forms chapter 5 is currently in press, also in the journal *Human Vaccines & Immunotherapeutics*. The paper that forms chapter 3 was recently accepted to the journal *Vaccine* pending minor corrections.

The following sub-sections outline the aims and rationale for each of these papers.

Chapter 2: Measuring trust in vaccination: A systematic review

In this systematic review we had three main aims. Firstly, we wanted to investigate how the current vaccine attitude and uptake research conceptualises and measures the concept of trust. Secondly, we wanted to compare this gathered research to the wider social-science literature on trust in health decisions, with the aim of identifying deficits in vaccine trust

measurements. Finally, we wanted to investigate the different dimensions of trust and their relationships to vaccine uptake.

Chapter 3: Antecedents and consequences of vaccination information-seeking and scanning: A systematic review

Building on the previously discussed health information-seeking literature, within this systematic review our aims were to:

- i. Review the prevalence of vaccine information-seeking and scanning across a range of vaccinations.
- ii. Identify a range of antecedents to vaccine information-seeking and scanning.
- iii. Examine information channel and source selection and their possible interactions with antecedents to vaccine information-seeking and scanning.
- iv. Examine the possible effects of vaccine information-seeking behaviour and vaccine information scanning on the vaccine decision-making process and vaccine uptake.

Chapter 4: Determinants of satisfaction with information and additional information-seeking behaviour for the pertussis vaccination given during pregnancy

In this chapter I report the first of two quantitative studies investigating the role of various decision related constructs in the behaviour of vaccine information-seeking. For this study we recruited women in the UK who had given birth during the previous 6 months. These women were asked to complete a survey containing psychometric scales related to the following constructs:

- Trust in healthcare professionals
- Trust in the healthcare system
- Psychosocial determinates of vaccine information-seeking behaviour
- Risk perception of vaccination during pregnancy

- Coping strategies

These constructs were used to predict the level of satisfaction held in the official information provided by their healthcare professional and the participant's vaccine information-seeking behaviour. In this chapter I also report the construct validity of the Psychosocial Determinants of Vaccine Information-Seeking Behaviour scale with confirmatory factor analysis.

Chapter 5: Do previously held vaccine attitudes dictate the extent and influence of vaccine information-seeking behaviour during pregnancy?

In this chapter I report the second of my two quantitative research studies investigating vaccination information-seeking behaviour. In this study we recruited pregnant women to participate in two linked surveys, one intended for early in their pregnancies (prior to 16 weeks) and one later in their pregnancies (after 36 weeks) with the purpose of capturing the effect of vaccine information-seeking behaviour over the course of the participants' pregnancies.

The study had three main aims. Firstly, we wanted to determine the extent to which previously held vaccine hesitant attitudes during pregnancy are associated with the extent and perceived influence of vaccine information-seeking behaviour. Secondly, we wanted to investigate the predictor variables of accepting the pertussis vaccine during pregnancy. Thirdly, we wanted to examine whether the strength of recommendation from a healthcare professional, the behaviour of vaccinating and the behaviour of seeking information during the decision-making process predict a change in attitude towards vaccination between early and late pregnancy.

These aims were investigated with the use of the following measured constructs:

- Vaccine confidence/hesitancy

- Risk perception of vaccination during pregnancy
- Decision conflict
- Strength of recommendation from a healthcare professional
- Vaccine information seeking behaviour
- Vaccine uptake

Chapter 6 & 7: Synthesis and Conclusion

In the final two chapters of the thesis I summarise the results from the four research chapters with respect to the previous literature in the field. I make conclusions and recommendations from this work and propose future research.

1.6 Role of the candidate

For the paper titled “Measuring trust in vaccination: A systematic review” (chapter 2) I share co-first authorship with Professor Heidi Larson. For this study, Professor Larson identified the research area and coordinated the initial search and screening process with the co-authors. I then updated the review, conducted the data extraction, synthesis and initial write up. Myself and Professor Larson then collaborated in the final manuscript write up with the co-authors.

For the remainder of the content included in this thesis, I designed the studies, collected the data, conducted the analyses and wrote the work present in each chapter and paper. Dr Pauline Paterson and Dr Miroslav Sirota supervised and gave regular feedback on this work.

1.7 Ethical clearance

Ethical approval for the research included in this thesis was granted by the LSHTM

Observational Ethics Committee. The reference numbers for the studies reported in chapter 4 & 5 were REF:11847 and REF:13898 respectively.

RESEARCH PAPER COVER SHEET

PLEASE NOTE THAT A COVER SHEET MUST BE COMPLETED FOR EACH RESEARCH PAPER INCLUDED IN A THESIS.

SECTION A – Student Details

Student	Mr Richard M Clarke
Principal Supervisor	Dr Pauline Paterson
Thesis Title	Vaccine information-seeking behaviour: its predictors and influence on vaccination during pregnancy

If the Research Paper has previously been published please complete Section B, if not please move to Section C

SECTION B – Paper already published

Where was the work published?	Human Vaccines & Immunotherapeutics		
When was the work published?	May 2018		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	No	Was the work subject to academic peer review?	Yes

**If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.*

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	
Stage of publication	Choose an item.

SECTION D – Multi-authored work

<p>For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)</p>	<p>I share co-first authorship with HL. HL identified the research area and coordinated the initial search and screening process with the co-authors prior to 2015. I then updated the review, conducted the data extraction on the gathered articles, synthesised the research and wrote the initial manuscript. Myself, HL and PP then collaborated on the final manuscript.</p>
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Student Signature: _____

Date: _____

Supervisor Signature: _____

Date: _____

2. Measuring trust in vaccination: A systematic review

2.1 Abstract

Vaccine acceptance depends on public trust and confidence in the safety and efficacy of vaccines and immunization, the health system, healthcare professionals and the wider vaccine research community. This systematic review analyses the current breadth and depth of vaccine research literature that explicitly refers to the concept of trust within their stated aims or research questions. After duplicates were removed, 19,643 articles were screened by title and abstract. Of these 2,779 were screened by full text, 35 of which were included in the final analysis. These studies examined a range of trust relationships as they pertain to vaccination, including trust in healthcare professionals, the health system, the government, and friends and family members. Three studies examined generalized trust. Findings indicated that trust is often referred to implicitly (19/35), rather than explicitly examined in the context of a formal definition or discussion of the existing literature on trust in a health context. Within the quantitative research analysed, trust was commonly measured with a single-item measure (9/25). Three studies used multi-item psychometric scales of trust. Three studies examined changes in trust, either following an intervention or over the course of a pandemic. The findings of this review indicate a disconnect between the current vaccine hesitancy research and the wider health-related trust literature, a dearth in research on trust in low and middle-income settings, a need for studies on how trust levels change over time and investigations on how resilience to trust eroding information can be built into a trustworthy health system.

Keywords: trust, confidence, vaccines, vaccination, immunization/immunisation

2.2 Introduction

Trust in the safety and efficacy of vaccines, trust in the individuals that administer vaccines or give advice about vaccination, and trust in the wider health system are all important factors which influence the vaccine decision making process (66–68). Trust is especially important

in light of the increasing number of vaccines recommended or required, as well as the complex safety and efficacy data which form the basis of vaccine policies and recommendations, which means that the public depends on health experts' competence, judgement and ability to interpret these data correctly and in the best interests of the public (69–74). Due to this complexity, vaccination decisions occur within the context of trust held in the various actors who interpret and make decisions based on the available evidence (75).

Vaccine-related trust also exists within the additional context of deeper, underlying trust in society at large. The historical legacy of trust/mistrust due to past interactions with official institutions additionally influences generalized trust in society (see figure 2). These varied histories and experiences mean that public trust in vaccines and immunization programs is highly variable and locally specific (4). Recognizing trust as a complex web of vaccine-related factors, as well as these external trust factors, can provide valuable insights into levers of vaccine acceptance, hesitancy or refusal.

2.2.1 Definitions of trust

The word 'trust' has been given a multitude of definitions within the health literature. At its core, trust becomes important when there is an implicit imbalance of power due to a high level of information asymmetry, where trusting individuals accept a vulnerable position in relation to a trusted party. In the context of vaccine decisions, one chooses to trust another to help one make a risk/benefit-based decision about which one has incomplete information (76–78).

Trust relationships require an active choice on behalf of the trusting party. Within this choice, trust-based cooperation assumes the trusted party firstly has the trusting individuals' best interests at heart and, secondly, has the expertise and ability to perform at a level of competence that is expected of them (79). As such, the process of trusting is sometimes described as a leap of faith (79,80).

We define trust as a relation that exists between individuals, as well as between individuals and a system, in which one party accepts a vulnerable position, assuming the best interests and competence of the other, in exchange for a reduction in decision complexity.

2.2.2 Trust relationships related to vaccination

Vaccine acceptance involves multiple levels of trust: trust in the **product** (the vaccine), the **provider** (the specific healthcare professionals or administrative staff that are involved in providing and administering vaccination), and trust in the **policy-maker** (the health system, government, and public health researchers involved in approving and recommending the vaccine) (81).

Trust in information needs to be considered both in terms of trust in the message itself (77,82,83) as well as in the source of that message (84,85). It is difficult to isolate ‘trust in information’ without considering the context of who created it and who is propagating it. In this review, we consider trust in information as nested within the trust held in the source of that information (82). Each source of information also possesses attributes that inform one’s assessment of its trustworthiness and reliability (86). Finally, perceptions of trustworthiness are subjective, since the same person or institution may be ascribed different levels of trustworthiness by different individuals, depending on those individuals’ personal experiences and biases (87).

2.2.3 External levers of trust

In addition to influences on trust in the context of immunisation, there are a number of external factors that influence trust.

2.2.3.1 *Generalized trust*

Generalized trust refers to the characteristic trait that differs between individuals with regard to their willingness to trust other members of society in general (88). When community-mindedness and civic participation are widespread in a society, with high average levels of trust, the concept of *generalized trust* forms part of the wider concept of *social capital*.

Historically, *generalized trust* has been said to play an important role in the flow of information from official sources to individuals in a community (89,90).

2.2.3.2 *Historical influences on trust*

How a health system has performed in the past, and the perceived values that it holds, play a substantial role in the process of building trust. Earle, Siegrist & Gutscher (44) describe the dual concepts of *social trust* and *confidence* within their “TCC Model of Trust, Confidence and Cooperation” (44,91,92). *Social trust*, closely relates to the similar concepts of benevolence, fidelity and morality in that its main requirement is a perceived set of shared values between individuals and a trusted party. *Confidence*, conversely, is described as the performance-based aspect of trust in which the competence and ability of the trusted party is assessed. If, therefore, a system is seen to discriminate against a particular population over a sustained period of time, it is likely that that population will lose trust in the system, which has implications for trusting and accepting the health information and interventions it provides in the future.

Religious and ethnic minorities are frequently cited in the healthcare trust literature as holding lower levels of trust in the health system and healthcare professionals (HCPs) (93–95). This distrust can be traced back to historical mistreatment and systematic neglect or abuse of these populations by health and governmental systems (96,97).

2.2.3.3 *External influencers*

Non-official sources of health information also influence decision making (98,99). Trust in these sources depends on perceived motive (*Does the source have my interests at heart?*) and ability (*Have they been competent and reliable in the past?*). These external influencers can include an individual’s own friends and family members, and non-official medical advice from religious organizations, alternative health networks, politicians and celebrities.

2.2.4 Mechanisms by which trust-based cooperation is built or eroded

Vaccination-related trust is considered in this review as a complex interaction between the core elements of trust in the product, provider and policy-maker and the external levers of trust – generalized trust, historical trust and other influences outside of the health system (see figure 2). Trust related to vaccination is strengthened when external levers align with the vaccine-related trust factors, and it is weakened when these are misaligned. If trust is lost in the vaccine-related players, then trust is more likely to be placed in other influencers, who may be indifferent to vaccination or may actually oppose it.

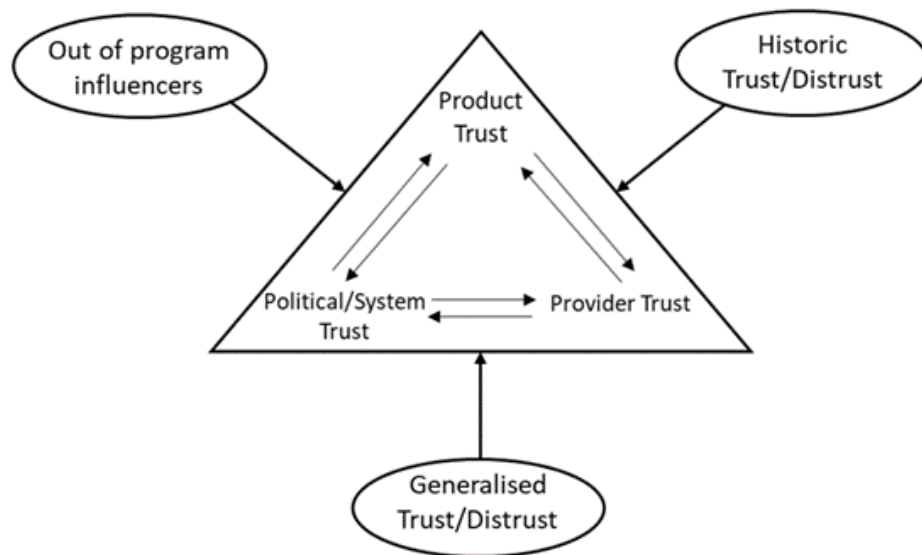


Figure 2: A visualisation of the trust relationship related to vaccination

2.3 Research Questions

The research questions this review intends to address are as follows:

- (1) How do vaccine studies, that specifically investigate trust, conceptualize and measure the concept of trust as a prominent factor in vaccine intention or uptake?
- (2) How does this measurement compare to the wider literature on trust in health-related decision-making?

2.4 Methods

This systematic review was part of a larger screening process conducted by the Vaccine Confidence Project from 2010 – 2014, the aim of which was to review all peer-reviewed articles and grey literature on public concerns about vaccines or vaccination programs. This led to the publication of the following systematic reviews (267, 268). In November 2017 I conducted an update to this original search and screening process.

2.4.1 Inclusion and exclusion criteria

To investigate the research questions for this particular systematic review, studies were included against the following eligibility criteria. Eligible studies included those regarding perceptions, concerns, confidence, attitudes, beliefs or uptake of vaccination that explicitly refer to trust or distrust in their stated aims, objectives or research questions. All research methodologies were eligible, however these methodologies ultimately fell under the category of cross-sectional or experimental studies. Qualitative studies were also included to supplement the quantitative findings.

Literature was excluded if it was (i) regarding non-human vaccines or vaccines not currently available; (ii) related to research and development of vaccines (unless explicitly about public trust, confidence, concern or hesitancy); (iii) non-peer-reviewed or non-English language studies.

2.4.2 Information Sources

Ten different medical and social science literature databases were searched for peer-reviewed articles on trust in vaccines or vaccination programs. These databases were Medline, Embase, PsychInfo, Cochrane, CINAHL Plus, Web of Science, LILACS, Africa-Wide Information, IBSS and IMEMR. Other than the time periods covered by each database, no additional time limitations were set.

2.4.3 Search strategy

A set of keywords was created to reflect the core concepts: vaccination and public perceptions, decision-making, and vaccination behaviour. Using Medline as a foundation database, these keywords were first refined and then systematically adapted (e.g. alternative truncations) and applied to the remaining databases.

In Medline, the keyword search terms were: vaccin\$, immunis\$ and immuniz\$ (Concept 1) and anxiety, attitude\$, awareness, behavio?r, belief\$, criticis\$, doubt\$, distrust\$, dropout\$, exemption\$, fear\$, hesitanc\$, trust, mistrust, perception\$, refusal\$, rejection, rumo?r, intent\$, controvers\$, misconception\$, misinformation, opposition, delay, dilemma\$, objecto?r\$, uptake, barrier\$, choice\$, mandatory, compulsory, concern\$, accepta\$, knowledge, parent\$ con\$, confidence, decision making, anti-vaccin\$, antivaccin\$.

The following MeSH terms were also included in the search: Vaccination, Vaccines, Mass Vaccination, Immunization and Immunization Programs and Public Opinion, Attitude to Health, Attitude, 'Health Knowledge, Attitudes, Practice', Patient acceptance of healthcare, Treatment Refusal, Parental Consent, Decision Making, Prejudice and Internet.

The search was initially run across all databases during the period of the 12th-19th November 2012 (conducted by the co-authors PP & JD) and again on 15th December 2014 (conducted by the co-authors PP & JD). I conducted a final update to this search strategy on 17th November 2017 for which a reduced version of the previous search terms was used, including only (vaccin\$ or immunis\$ or immuniz\$) and (distrust\$ or trust or mistrust or rumo?r) and narrowed the year range to 2015-2017.

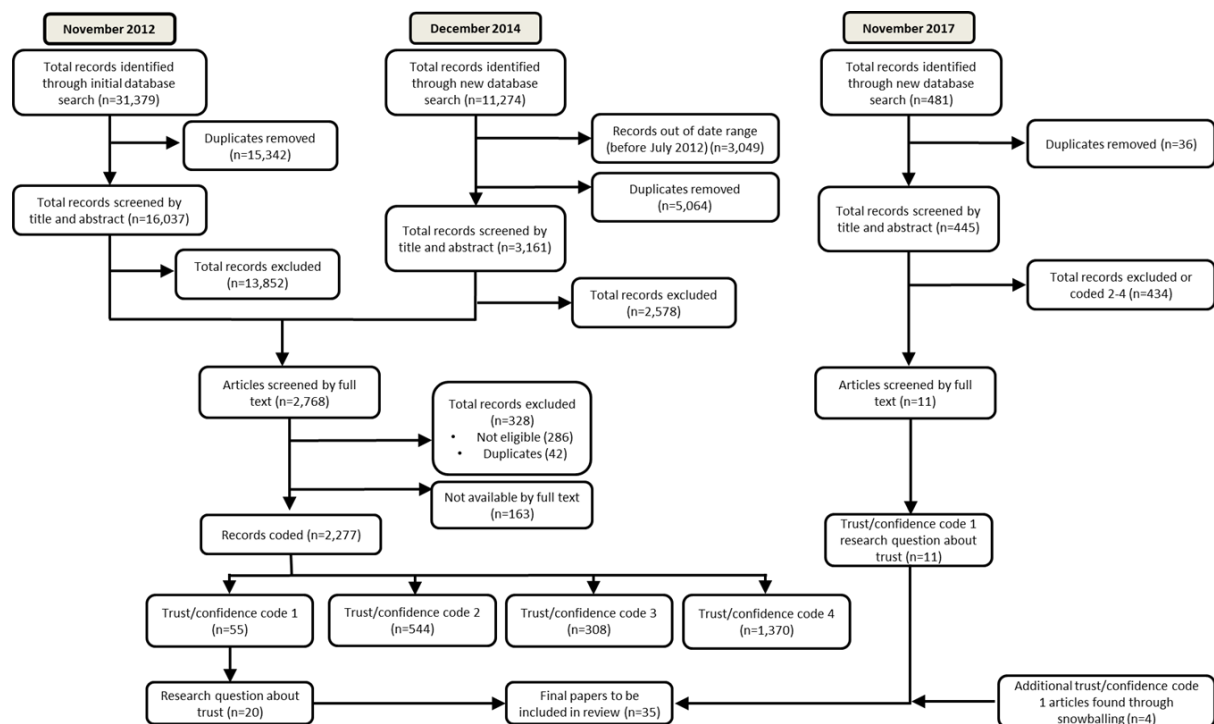


Figure 3: Search flow diagram for measurement of trust in vaccination systematic review

2.4.3 Data extraction

The screening of titles and abstracts for the 2012 and 2014 search periods were shared between at least two authors and a sample of studies was independently coded to ensure consistency. The included papers were assigned a numerical trust code based on the following criteria:

- Code 1: Primary research question about trust.
- Code 2: Trust referred to as a dimension, factor or variable (i.e. trust is identified in the results or named as a determinant related to vaccine acceptance, although not explicitly investigated in the research question).
- Code 3: Trust is mentioned in a peripheral way (e.g. in discussion section, but not in methods or results).
- Code 4: No reference to trust.

The papers coded as trust code 1 were then screened by full text (by co-authors PP and JD). After duplicates were removed, 19,643 articles were screened by title and abstract and 2,779 articles were screened by full text. Twenty articles were then put forward for this review. These papers were combined with the 15 additional articles I found during the 2017 search process, culminating in a total of 35 articles in the final review. I developed a data extraction spreadsheet in excel and extracted details regarding the study's country, vaccine, population of focus, study methodology, definition of trust within the study's aim/research question/objective, aspect of trust examined (as categorised by the wider trust literature illustrated in Figure 2), and specific questions used to examine trust, and their main trust related findings. The complete extractions can be seen in Table 1 and Appendix B.

Table 1: Characteristics of quantitative studies

	Year data collected	Location	Vaccine(s) of focus	Study methodology	Number of participants	Cohort or comparison	Demographic of focus	Aim of study/research question
Berry, Gold, Ryan, Duszynski & Braynack-Mayer (2012) ^[100]	2011	Australia	Childhood, General	Questionnaire/survey	2002	Cohort	Parents, Urban and rural	Trust features in the main examined factors <i>“we examined consent preferences, trust in the protection of privacy for data linkage, and attitudes towards vaccination in terms of its public health benefit, safety, and effectiveness.”</i>
Casiday, Cresswell, Wilson & Panter-brick (2006) ^[101]	2004	United Kingdom	Childhood, MMR	Questionnaire/Survey	996	Comparison	Parents	Trust featured in one of the 4 study aims. <i>“To determine the level of agreement, among both MMR-accepting and MMR-refusing parents in a PCT population, with statements about (a) the safety of MMR vaccine, (b) single-antigen vaccines, (c) the importance of immunisation, and (d) trust in medical authority.”</i>
Cheng, Huang, Shaw, Kao & Chueh (2010) ^[112]	2009	Taiwan	Postpartum, Pertussis	Questionnaire/Survey	1207	Comparison	Mothers, Postpartum	Trust featured within aims of study. <i>“The aims of this study were to explore factors that influenced postpartum women’s decisions regarding pertussis vaccination and to determine if women’s concerns about vaccine safety and efficacy were related to their information needs and trust in the content of information provided, or both”</i>
Chuang, Huang, Tseng, Yen & Yang (2015) ^[121]	2014	Taiwan	Adult, Pandemic influenza	Questionnaire/Survey	1745	Cohort	Adults	Trust featured within study hypothesis. <i>“The hypothesis proposed was that each component of social capital—bonding, bridging, and linking—contributed to a person’s intent to receive a vaccine, wear a face mask, and wash hands more frequently during an outbreak of influenza pandemic.”</i>
Cooper, Hernandez, Rollins, Akintobi & Mcallister (2017) ^[122]	2014	USA	Adult, HPV	Questionnaire/Survey	1203	Comparison	Adults, Males	Trust featured in one of the 2 study aims. <i>“the purpose of this study is to: (1) assess awareness of men about HPV and HPV vaccine by race/ethnicity and (2) examine the association of trust in information from physicians about cancer and even hearing about HPV and HPV vaccine.”</i>

Das & Das (2003) ^[123]	1998	India	Childhood, General	Questionnaire/Survey	146	Cohort	Parents	Trust not explicitly mentioned in a research question but formed one of main examined relationships. <i>“we examine the relationship between community knowledge regarding vaccination and community trust in the provider of vaccinations, and show how these two factors jointly determine the demand for preventive health services.”</i>
Fowler, Baggs, Weintraub, Martin, McNeil & Gust (2006) ^[124]	2002-2004	USA	Adult, Anthrax	Questionnaire/Survey	404	Comparison	Laboratory workers	Trust featured within aims of study. <i>“The purpose of this study was to determine (1) the factors that influenced laboratory workers’ decisions to accept or decline AVA, and (2) if laboratory workers’ concern about AVA safety was related to their information needs and trust in the information provided”</i>
Freed, Clark, Butchart, Singer, & Davis (2011) ^[125]	2009	USA	Childhood, General	Questionnaire/Survey	1552	Cohort	Parents	Trust primary focus of study. <i>“Objective: To assess what proportion of parents trust vaccine information from different sources and whether different groups of parents vary in their trust of such information”</i>
Freimuth, Jamison, An, Hancock & Quinn (2017) ^[126]	2015	USA	Adult, Influenza	Questionnaire/Survey	1630	Comparison	Adults, African American and White	Trust featured in all four of the study research questions. <i>“1. Do African Americans and Whites differ in their level of generalized trust, as well as in their levels of trust in the flu vaccine and trust in the vaccine process? 2. What is the differential role of demographics, racial factors, and ideological beliefs in predicting generalized trust, trust in the flu vaccine and trust in the vaccine process across African Americans and Whites? 3. What is the differential role of generalized trust in predicting trust in the flu vaccine and trust in the vaccine process across African Americans and Whites? 4. Controlling for demographics, racial factors, ideological beliefs and generalized trust, what is the differential role of psychosocial variables in</i>

								<i>predicting trust in the _u vaccine and trust in the vaccine process across African Americans and Whites?”</i>
Fu, Zimet, Latkin & Joseph (2017) ^[127]	2012-2014	USA	Adolescent, HPV	Questionnaire/Survey	400	Comparison	Parents, African American	Research question not explicitly mentioned but trust features prominently within main examined relationships. <i>“The current study examined the dual associations of parental trust in HCPs for vaccine advice and strength of HCP vaccination recommendations with HPV vaccine acceptance among African American parents”</i>
Gilles et al (2011) ^[102]	2009	Switzerland	Adult, Pandemic Influenza	Questionnaire/Survey	601	Comparison	Adults	Research question not explicitly mentioned but trust features prominently within main examined relationships. <i>“Trust in medical organizations measured among Swiss residents in the Summer of 2009 is the only variable that predicts actual vaccination status during the Winter 2009 pandemic (H1N1) 2009 vaccination campaign”</i>
Grabenstein, Guess, Hartzema, Koch & Konrad (2002) ^[103]	1998	USA	Adult, Influenza	Questionnaire/Survey	2090	Cohort	Adults, 65+ yrs	Research question not explicitly mentioned but trust features within main examined relationships. <i>“We explored the hypothesis that demographic differences and perceptions of access, convenience, and trust would explain choices between traditional and non-traditional vaccine providers”</i>
Kolar, Wheldon, Hernandez, Young, Romero-Daza & Daley (2015) ^[104]	2011	USA	Adult, HPV	Questionnaire/Survey	711	Comparison	Adults, racial/ethnic minority students	Trust features within study hypothesis. <i>“We hypothesized that higher mistrust and greater difficulty talking to health-care providers (HCPs) would be associated with lack of preventative health behaviors in this population”</i>
Lee, Whetten, Omer, Pan & Salmon (2016) ^[105]	2002-2003	USA	Childhood, General	Questionnaire/Survey	2445	Comparison	Parents	Trust forms the main findings of the study. <i>“These data offer the potential to illuminate how distrust contributes to vaccine hesitancy and vaccine refusal in parents of school-aged children by looking at questions including where parents get their vaccine information, whether they use complementary/alternative medicine (CAM)</i>

								<i>practitioners, and how they feel about immunization requirement laws.”</i>
Manika, Ball, Stout & Stout (2014) ^[106]	Does not state	USA	Adult, HPV	Questionnaire/Survey	117	Comparison	Adults, Females, University students	Trust featured in one of the 4 study research questions. <i>“How do traditional consumer factors (knowledge, familiarity, attitudes, and trust of direct to consumer advertising for a brand of the HPV vaccine) differ between those who have and have not received the vaccine?”</i>
Marlow, Waller & Wardle (2007) ^[107]	2006	United Kingdom	Adolescent, HPV	Questionnaire/Survey	684	Comparison	Parents, Mothers	Trust featured within aims of study. “To examine the association between general vaccine attitudes, trust in doctors and the government, past experience with vaccination, and acceptance of HPV vaccination”
McPhillips, Davis, Marcuse & Taylor (2016) ^[108]	2000	USA	Childhood, Rotavirus	Questionnaire/Survey	558	Cohort	HCPs, Physicians	Trust mentioned prominently within objective of study. <i>“To determine how the withdrawal from the market of the rotavirus vaccine has affected physicians’ trust in vaccine safety mechanism, future adherence to vaccine recommendations, and willingness to use a new rotavirus vaccine.”</i>
Moran, Frank, Chatterjee, Murphy & Baezconde-Garbanati (2016) ^[109]	Does not state	USA	Childhood, General	Questionnaire/Survey	761	Cohort	Parents, ethnic minority and white	Trust features within the second aim of the study. <i>“A secondary aim of this study was to investigate the relationships between vaccine safety concerns, information scanning, and trust in interpersonal sources of information among three ethnic groups—African American, Mexican American and non-Hispanic White.”</i>
Quinn, Jamison, Freimuth, An, Hancock & Musa (2016) ^[110]	2016	USA	Adult, Influenza	Questionnaire/Survey	1643	Comparison	Adults, African American and White	Trust features within all three of the study’s research questions <i>“(1) Are there differences between African Americans and Whites regarding the influenza vaccine in terms of vaccine knowledge and attitudes including trust,</i>

								<p><i>risk perception, vaccine beliefs, vaccine hesitancy and confidence, and social norms?</i></p> <p><i>(2) Do racial factors associated with being an African American or White in the U.S. relate to vaccine knowledge and attitudes including trust, risk perception, vaccine beliefs, vaccine hesitancy and confidence, and social norms?</i></p> <p><i>(3) Do racial factors relate to vaccine behaviors, and does vaccine knowledge and attitudes including trust, risk perception, vaccine beliefs, vaccine hesitancy and confidence, and social norms, mediate that relation?"</i></p>
Raude, Fressard, Gautier, Pulcini & Peretti (2016) ^[111]	2013-14	France	Childhood, General	Questionnaire/Survey	1582	Cohort	HCPs, GPs	<p>Trust formed the primary focus of study.</p> <p><i>"Our underlying hypothesis was that the influence of trust in institutions on GPs' Vaccine recommendation practices may be mediated to a large extent by three proximal variables: confidence in vaccine (beliefs about their safety), complacency (beliefs about the importance of immunization), and self-efficacy."</i></p>
Ronnerstrand (2013) ^[113]	2009-2010	USA	Adult, Pandemic influenza	Questionnaire/Survey	28 798	Comparison	Adults	<p>Research question not explicitly mentioned but trust features prominently within main examined relationships.</p> <p><i>"The current paper investigates the association between contextual state-level generalized trust and individual 2009 A(H1N1) pandemic immunization in the American states"</i></p>
Scherer, Shaffer, Patel & Zikmund-Fisher (2016) ^[114]	2014	USA	Adolescent, HPV	Experimental	1259	Experimental, comparison	Adults	<p>Research question not explicitly mentioned but trust features prominently within main examined relationships.</p> <p><i>"In this study, we tested the possibility that open communication about VAERS – how it works, what it is for, and what the database contains – could improve trust in the accuracy and honesty of the CDC's conclusions about vaccine safety and increase vaccine acceptance by concretely illustrating how few adverse events occur compared to the number of vaccinations given, as well as highlighting the CDC's efforts to monitor and document possible harms."</i></p>

Taylor-Clark, Blendon, Zaslavsky & Benson (2005) ^[115]	2002	USA	Adult, Smallpox	Questionnaire/Survey	1006	Comparison	Adults	<p>Research question not explicitly mentioned but trust features prominently within main examined relationships.</p> <p><i>“In this study we analyse a recent survey to determine the effects of a set of variables, including aspects of trust in government that have been found in previous studies to influence public opposition to compulsory government health policies, on opinions about compulsory vaccination and quarantine.”</i></p>
Tucker-Edmonds, Coleman, Armstrong & Shea (2011) ^[116]	2009	USA	Adult, Pandemic influenza	Questionnaire/Survey	173	Comparison	Adults, Pregnant women	<p>Trust featured in one of the 2 study aims.</p> <p><i>“the primary aim of this study is to assess pregnant women’s risk perceptions, worry, and health care distrust in relation to the H1N1 pandemic flu and the H1N1 flu vaccine; and to determine if these factors relate to the mothers’ intentions to receive the vaccines”</i></p>
Wada & Smith (2015) ^[117]	2014	Japan	Undefined	Questionnaire/Survey	3140	Cohort	Adult	<p>Trust features within the aim of the study</p> <p><i>“the current study was undertaken to investigate associations between mistrust for governmental recommendations on vaccination and social background in the working-age population of Japan.”</i></p>
Weerd, Timmermans, Beaujean, & Oudhoff (2011) ^[118]	2009	The Netherlands	Adult, Pandemic influenza	Questionnaire/Survey	8060	Comparison	Adults	<p>Trust featured in two of the 3 study aims.</p> <p><i>“The aim of the study was to identify and describe possible changes in the public’s level of government trust, risk perception, and intention to adopt protective measures. Secondly, we wanted to identify whether government trust and risk perception were positively associated with an intention to adopt protective measures, including vaccination.”</i></p>
Won, Middleman, Auslander & Short (2015) ^[119]	2012-2013	USA	Childhood, General	Experimental	1608 / 844	Experimental, intervention	Parents	<p>Trust formed the primary focus of study.</p> <p><i>“Purpose: To determine variables associated with parental trust in a school-located immunization program (SLIP) and the effect of trust-building interventions on trust and participation in SLIPs.”</i></p>

Wu et al (2008) ^[120]	2003	USA	Childhood, General	Questionnaire/Survey	228	Cohort	Parents, Mothers, Postpartum	Trust featured in one of the 3 study objectives. <i>“The objectives of the study were to assess (1) the frequency that mothers have beliefs that are consistent with the promoters or inhibitors of vaccination, (2) the frequency that mothers do not trust their providers and what determines trust or lack of trust, and (3) maternal knowledge regarding vaccination.”</i>
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Table 2: Characteristics of qualitative studies

	Year data collected	Location	Vaccine(s) of focus	Study methodology	Demographic of focus (no° participants)	Data analysis process	Aim of study/research overview
Brownlie & Howson (2006) ^[128]	1998 and 2001	UK	Childhood, MMR	Focus groups and in-depth interviews	HCPs ,(N=58)	Thematic analysis	No specific aim intended however the study reports a reanalysis of previous related data in which the authors examine “ <i>theoretical links between risk, trust and knowledge in relation to the governance of health</i> ”
Bunton & Gilding (2013) ^[129]	2011	Australia	Adult, HPV	Exploratory workshops	Adults, Women (N=46)	Content analysis based partially on a grounded theory approach	The study investigates women’s knowledge and awareness about cervical cancer diagnostics and how they might be improved. The study coincided with the roll out of the HPV mass vaccination campaign.
Harris, Chin, Fiscella, Humiston & York (2006) ^[130]	2004-2005	USA	Adult, Influenza	In-depth interviews	Adults, 65+ yrs (N=20)	Content analysis based partially on a grounded theory approach	The study investigates the role of trust of medical institutions in the decision by elderly black Americans to receive pneumococcal and influenza vaccinations.
Hilton, Petticrew, & Hunt (2007) ^[131]	2002-2003	UK	Childhood, MMR	Focus groups	Parents (N=72)	Thematic analysis	To examine parents’ views on the role the media, politicians and health professionals have played in providing credible evidence about MMR safety
King & Leask (2017) ^[132]	2010-2011	Australia	Childhood, Influenza	In-depth interviews	Parents (N=25)	Content analysis based partially on a grounded theory approach	“ <i>This qualitative study aimed to explore the impact of the vaccine suspension on parental knowledge, attitudes, trust, information needs, and intent related to influenza vaccination and broader immunisation programs</i> ”
Senier & Senier (2016) ^[133]	2004	USA	Childhood, general	In-depth interviews	Parents (N=20)	Thematic analysis	To examine the relationship between risk perception, trust and information.

Quinn, Jamison, Musa, Hilyard & Freimuth (2016) ^[134]	2016	USA	Childhood, general	Focus groups	Adults, African American and White (N=118)	Thematic analysis	<p>1. What is the difference in the degree of vaccine hesitancy between African American and White adults related to seasonal influenza immunization?</p> <p>2. What impact do cultural, attitudinal and social differences have on vaccine hesitancy?</p> <p>3. Are the vaccine narratives of both African American and White adults accurately reflected in the Three Cs framework?</p>
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2.5 Results

2.5.1 Characteristics of studies

Of the 35 included studies, over half (21/35) were conducted in the USA. Two studies were conducted in Taiwan, one study was conducted in India, and one in Japan. The remaining nine studies were conducted in either Western Europe or Australia. The target vaccine/vaccination program varied between studies with 11 studies focusing on childhood vaccinations (standard vaccine schedule or specifically MMR, rotavirus, or influenza vaccine), 14 studies focusing on adult vaccinations (HPV, seasonal influenza, pandemic influenza, postpartum pertussis, smallpox, or anthrax vaccine) and three studies focusing on the adolescent HPV vaccination. Investigated trust factors predominantly included the information from and/or the trust placed in the health system, healthcare professionals, the government, science or trusted others (e.g. friends, family, alternative healthcare professionals, non-official internet sources, celebrities). Three studies investigated the concept of *generalized trust*.

2.5.2 Quantitative studies

2.5.2.1 Context of trust

Of the 28 quantitative studies reviewed, ten studies examined trust in the context of vaccine uptake, six studies examined trust in the context of intention to vaccinate, ten studies examined factors associated with vaccine trust and two studies examined health care professionals trust in the health system and their likelihood to give a strong recommendation to vaccinate. Findings from these studies indicated that combined trust in the health system, trust in science and trust in government have an indirect effect on the likelihood of health care professionals recommending vaccination (111).

All studies measured some aspect of our vaccine trust model (see figure 2). Factors outside of the specific vaccine or vaccination program were measured less frequently, with three studies examining generalized trust (113,121,126), three studies examining out-of-program

influences (109,117,125) and one study examining changes in trust over time (118). Wada and Smith (117) were the only study to have referenced the concept of trustworthiness and their findings indicated that respondents who did not trust a vaccination recommendation were more likely to consider other non-medical sources as being trustworthy.

2.5.2.2 Definition and Measurement overview

Eighteen of the quantitative studies did not contain a definition of trust or a discussion of the concepts present within the trust literature, despite explicitly mentioning trust within their aim or research question (100,103,104,106–109,111,112,114,116,117,120,122–125,127). By leaving the definition of trust implicit, these papers created ambiguity around this core concept. Four studies (101,102,105,119) included some brief mentions of relevant trust concepts (e.g. a distinction between social trust and confidence). Only six studies defined trust through extensive reference to previously published peer-reviewed trust literature (110,113,115,118,121,135) (see tables 3 and 4).

Table 3: Definitions of trust across reviewed literature

	Trust was not explicitly defined	Hints made towards trust concepts mentioned in the literature	Trust defined through extensive use of trust literature.
Vaccine uptake	Cheng et al (2010) ^[39] Das & Das (2003) ^[42] Fowler et al (2006) ^[43] Fu et al (2017) ^[46] Manika et al (2014) ^[51] Kolar et al (2015) ^[49]	Casiday et al (2006) ^[38] Gilles et al (2011) ^[47] Lee et al (2016) ^[50]	Ronnerstrand (2013) ^[57]
Intention to vaccinate	Marlow et al (2007) ^[52] Scherer et al (2016) ^[58] Tucker-Edmonds et al (2011) ^[60]		Taylor-Clark et al (2006) ^[59] Weerd et al (2011) ^[62] Chuang et al (2015) ^[40]
Predictors of trust in relation to vaccination	Berry et al (2012) ^[37] Cooper et al (2017) ^[41] Freed et al (2011) ^[44] Grabenstein et al (2002) ^[48] Wu et al (2008) ^[64] Moran et al (2015) ^[54] Wada & Smith (2015) ^[61]	Won et al (2015) ^[63]	Freimuth et al (2017) ^[45] Quinn, Jamison, Freimuth, An, Hancock & Musa (2016) ^[55]
HCP intention to recommend vaccine	McPhillips et al (2016) ^[53] Raude et al (2016) ^[56]		
Qualitative research	Harris et al (2006) ^[67]	Hilton, Petticrew & Hunt (2007) ^[68] King & Leask (2017) ^[69]	Brownlie & Howson (2006) ^[65] Bunton & Gilding (2013) ^[66] Senier & Senier (2016) ^[70] Quinn, Jamison, Musa, Hilyard & Freimuth (2016) ^[71]

Table 4: The measurement of trust across reviewed quantitative literature

	Measures of trust not reported	Used implicitly defined measures of trust	Used literature-aligned measures of trust	Used literature-informed measures of trust	Used multi-item psychometric scale of trust
Vaccine uptake	Das & Das (2003) ^[42]	Cheng et al (2010) ^[39]	Casiday et al (2006) ^[38]	Lee et al (2016) ^[50]	Ronnerstrand (2013) ^[57]
	Gilles et al (2011) ^[47]	Fowler et al (2006) ^[43]			Kolar et al (2015) ^[49]
	Manika et al (2014) ^[51]	Fu et al (2017) ^[46]			
Intention to vaccinate			Marlow et al (2007) ^[52]	Taylor-Clark et al (2006) ^[59]	Tucker-Edmonds et al (2011) ^[60]
			Scherer et al (2016) ^[58]	Weerd et al (2011) ^[62]	
				Chuang et al (2015) ^[40]	
Predictors of trust in relation to vaccination	Berry et al (2012) ^[37]	Cooper et al (2017) ^[41]	Won et al (2015) ^[63]	Freimuth et al (2017) ^[45]	
		Freed et al (2011) ^[44]	Wu et al (2008) ^[64]		
		Grabenstein et al (2002) ^[48]			
		Moran et al (2015) ^[54]			
		Wada & Smith (2015) ^[61]			
HCP intention to recommend vaccine		Quinn, Jamison, Freimuth, An, Hancock and Musa (2016) ^[55]			
		McPhillips et al (2016) ^[53]			
		Raude et al (2016) ^[56]			

A full reporting of measures used can be found in the supplemental materials (Appendix B)

Among the 25 studies that reported their measures, only three used multi-item psychometric scales or widely used measures of trust (104,113,116). Five studies constructed measures of trust explicitly informed by published trust literature (105,115,118,121,135). A further five studies, while not explicitly mentioning the trust literature, used metrics that reflected aspects of confidence and social trust as they are conceptualized in the literature (101,107,114,119,120). The remaining studies (10 of 25) measured trust with a single-item measure that either asked the respondents to indicate their level of trust in the trust subject (e.g. individual services, or the system) or in the information provided (103,109–112,117,122,124,125,127).

2.5.2.3 Studies focused on vaccination uptake

Within the quantitative studies that examined the relationship between trust and vaccine uptake 7/10 studies reported measuring trust in the health system, 5/10 reported measuring trust in primary health care professionals, 4/10 reported measuring trust in government and 1/10 reported measuring *generalized trust*. No studies focusing on vaccine uptake examined other subjects of trust such as trust in science, trust in the media or trust in influential individuals outside the immunization system (such as friends and family, religious or community leaders, celebrities, alternative healthcare professionals).

Trust in the health system was reliably found to predict vaccine uptake in regression analyses (102,106) or was found to be significantly associated with retrospective reports of a vaccine uptake (101,104,112,124). A positive association was also identified between trust in health care professionals and vaccine uptake in 4/6 studies measuring this factor (101,105,106,127).

Three out of the four studies that examined trust in government found a significant positive association between trust and vaccine uptake (101,105,127). The one study (113) investigating *generalized trust* found a significant positive association between generalized trust and vaccine uptake.

One study used a multi-item psychometric trust measure (104) – the Group-Based Medical Mistrust Scale (136). Ronnerstand (113) and Lee et al (105) used the standard *generalized trust* question (88) and use an adapted version of the Trust in Physician Scale (137) respectively.

2.5.2.4 Studies focused on ‘intention to vaccinate’

Among the six studies that investigated intention to vaccinate, trust in the health system was the most-measured trust factor (4/6 studies) (107,115,116). Two studies measured trust in governments (118,121), one study measured trust in health care professionals (107) and one study measured generalized trust (121). All trust factors measured were found to be positively associated with an increased intention to vaccinate.

Three of the studies made a distinction between *social trust* and *confidence* (115,116,118), one of which mentions the TCC Model of Trust, Confidence and Cooperation specifically (118). One study used a multi-item psychometric trust measure (116) in the form of The Healthcare System Distrust Scale (138).

Additionally, an experimental study by Scherer et al (114) indicated that showing individuals a summary of the vaccine adverse effect data slightly increased trust in the HCS, however showing detailed reports greatly reduced trust.

2.5.2.5 Studies that measured factors associated with vaccine trust

In ten studies, multiple trust factors were identified (100,103,109,120,122) and formed the primary focus of the study (110,117,119,125,135). Measurement of trust within this subset of studies did not utilise psychometric measures of trust or explicitly use the existing trust literature to inform their measurement items.

Factors associated with a lower level of trust in the health system or a health care professional included being in a lower income bracket (119,120) and belonging to an ethnic minority (110,119,122,135). While factors such as previous participation in a school-based

immunization program (119), perceived importance of the vaccine (119), and the use of Medicaid over private insurance (119) were associated with higher levels of trust in the health system or a health care professional. Further findings indicated a range of subjects that were trusted to different degrees by the respondents (109,117,125).

2.5.2.6 Studies focused on healthcare professionals

Two studies with a focus on trust from the perspective of health care professionals met our inclusion criteria (108,111). Of these, one study focused primarily on trust (111) and the other explored a range of vaccine acceptance factors, including trust (108). Neither of the two studies utilised psychometric measures of trust, nor did they explicitly use previous trust literature to inform the development of their measures.

2.5.3 Qualitative Studies

The findings from the qualitative studies appeared more representative of the wider healthcare trust literature than those of the quantitative studies. Of the seven qualitative studies, four studies thoroughly defined the concept of trust with reference to peer reviewed literature (128,129,133,134) and a further two studies referenced at least some of the healthcare-trust literature (131,132). Only in one study was the definition of trust left implicit (130).

One of the common themes reported was the interaction between trust, information and conflicts of interest due to financial incentives. A perceived trust violation was said to occur when health care professionals, the government or the wider health system were seen to financially profit from vaccination which, in turn, often led to a perception of bias in the information provided by these individuals or institutions. Perceived trust violations were reported in four of the seven studies (128,129,131,133), one of which indicated that health care professionals themselves cited financial incentives as possibly damaging the trust relationships with their patients (128). Hilton, Petticrew & Hunt (131) suggest that when

financial incentive-based mistrust occurs, trust may then be transferred to other trusted parties that are perceived to be free of any ‘hidden agenda.’

Further findings from Harris et al (130) and Quinn et al (134) indicate that mistrust in the health system by African Americans may be a symptom of long-term experiences of racial prejudice. Historical medical injustices and medical malpractice were seen to negatively affect trust however trust was said to recover when medical care was good over time (132).

2.6 Discussion

2.6.1 Measurements of trust

2.6.1.1 The absence of psychometric measures of trust

A 2013 systematic review by Ozawa & Sripad (139) on the measurement of health-related trust identified and evaluated 45 multi-item psychometric measures of health system related trust. Within our vaccine-specific review only three studies (104,105,116) used or adapted any of the trust measures included in the Ozawa & Sripad review, indicating a disconnect between vaccine-related trust research and the wider health-related trust literature.

This lack of underlying theory and validity with respect to the measurement of trust was also prevalent across many of the studies that constructed their own measures. For example, 10 out of the 25 studies that reported their measures cited the use of a single question to measure an aspect of trust, many of which dichotomized their Likert scale variable for later analysis further reducing the sensitivity of their findings.

Within the qualitative research, it was evident that distrust based on value misalignment was particularly likely when health care professional financial incentives for vaccinating were identified (128,129,131,133). This form of distrust is distinct from the distrust caused by perceptions of incompetence. Currently this distinction is left largely unexamined by much of the vaccine-related trust research. The inclusion of a psychometric scale or the custom design of two trust questions (one related to perceived performance/reliability and one related to

perceived motives and morality/values of a trusted party), would allow for a far more nuanced exploration of these different trust dynamics.

2.6.1.2 Measurement focused on trust in the health system or healthcare professionals

While trust is shown to have a positive effect on vaccination intention and uptake in most of the studies reviewed, few explored trust factors or concepts beyond those of trust in the health system (21 studies), the government (10 studies) or health care professionals (9 studies). Only two studies (42,52) specifically measured trust in the vaccine (e.g. ‘*Overall, how much do you trust the flu vaccine?*’ (42)). Furthermore, factors outside of the vaccination program were also rarely measured (109,113,117,118,121,125,135). Future research would benefit greatly from investigating further interactions between the various dimensions of trust related to vaccination.

2.6.2 Historic trust and under representation of low- and middle-income countries

The theme of historic neglect or abuse from a government or health system was often seen as an underlying reason for distrust in vaccines among marginalized groups (130,132,134).

Some of the quantitative studies examined these themes through the comparison of trust levels between different ethnic groups (104,109,110,126,127). While this is without doubt an important topic to study, the equally important concept of trustworthiness of the systems themselves is noticeably absent. By shifting the burden of distrust onto the minority individual or community, and away from the trustworthiness of institutions, the genuine drivers of trust and distrust may actually be obscured.

The level of diversity within the studies that met our inclusion criteria reflects a narrow focus on high-income countries. Only one study was based in a middle-income country (123) and none of the studies focused on low-income countries. With trust playing such a key role in influencing vaccine acceptance, more research is needed in middle and low-income settings

to truly understand whether findings in high income countries have relevance in low and middle-income countries.

2.6.3 Limitations

This review focused tightly around the concept of trust being mentioned within the stated aims or research questions of the included papers. This, potentially, biased our results towards only including studies in which authors considered their findings related to trust to be of particular interest. As such, papers that measure the concept of trust, but give it little in the way of recognition, are likely absent from this review. It is therefore noteworthy that, even with such a constraint, the reported studies lacked methodological rigour when measuring trust. Further to this point, it is likely that we were over reliant on the term trust within the search and selection procedure, and as such likely missed the occasional study that examined certain sub-constructs of trust which did not explicitly include the term trust in their aims or research question (for example those that examined the perception of incentives within the healthcare system).

Throughout this review, no formal quality assessment of the included papers was undertaken. However, through the investigation of the measurement of trust within these studies, it is possible to conclude that many of the studies lacked a deep and literature informed investigation where this particular factor is concerned.

2.7 Conclusion

Even within vaccine studies that include the concept of trust within their primary research question, trust can often be an ill-defined and loosely-measured concept. The prevalence of single-item measures, where the definition of trust was left as implicit, indicates that a thorough understanding of trust as it relates to vaccine acceptance is currently under-researched. Furthermore, a lack of experimental or longitudinal studies that investigate how trust can be eroded or built over time demonstrate that there is great potential for new

contributions to our understanding of the temporal dynamics and levers of trust in relation to vaccination.

RESEARCH PAPER COVER SHEET

PLEASE NOTE THAT A COVER SHEET MUST BE COMPLETED FOR EACH RESEARCH PAPER INCLUDED IN A THESIS.

SECTION A – Student Details

Student	Mr Richard M Clarke
Principal Supervisor	Dr Pauline Paterson
Thesis Title	Vaccine information-seeking behaviour: its predictors and influence on vaccination during pregnancy

If the Research Paper has previously been published please complete Section B, if not please move to Section C

SECTION B – Paper already published

Where was the work published?			
When was the work published?			
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Choose an item.	Was the work subject to academic peer review?	Yes

**If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.*

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	Vaccine
Please list the paper's authors in the intended authorship order:	Mr Richard Clarke, Dr Pauline Paterson & Dr Miroslav Sirota
Stage of publication	Undergoing revision

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)

I designed the studies, collected the data, conducted the analyses and wrote the manuscript. Dr Pauline Paterson and Dr Miroslav Sirota supervised and gave regular feedback during this process and confirmed the work before submission.

Student Signature: _____

Date: _____

Supervisor Signature: _____

Date: _____

3. Antecedents and consequences of vaccination information seeking and scanning: A systematic review.

3.1 Abstract

Health information seeking behaviour and health information scanning are well-documented features of the health decision-making process. One such decision where information plays a key role is in that of vaccination. While vaccine information distributed by a healthcare professional is supported by scientific evidence; false information, unreliable information and misinformation is pervasive in some interpersonal communities and online. Evidence suggests that reading such unreliable information increases vaccine hesitancy and ultimately may lead to refusal or delay of vaccination. What is less clear however, are the information practices that ultimately yield unreliable information.

To that end, we conducted a systematic literature review of vaccine information-seeking behaviour and scanning. We aimed to 1. Review the prevalence of vaccine information-seeking behaviour and vaccine information scanning, 2. Identify a range of antecedents for such behaviours. 3. Examine the influence of vaccine information channel and source selection. 4. Examine the effects of vaccine information seeking behaviour on vaccine decision making and vaccine uptake. All quantitative and qualitative observational studies across a range of childhood, adult and maternal vaccine were eligible for inclusion in the review. We identified 702 articles through a systematic search of seven common databases and additional snowballing. After screening the abstract of the papers, we included 52 in the review.

Results indicated that the proportion of participants seeking information about vaccination differed between vaccine/vaccine type, with a weighted-average of 26% of participants searching for information in regards to the HPV vaccine, 47% for childhood vaccines and 82% for the H1N1 influenza vaccine. For healthcare professionals making a decision about

their own seasonal influenza vaccination, those that accepted the vaccine were significantly more likely to have sought out information about the vaccine.

In addition, we identify a range of demographic, situational and socio-cognitive antecedent variable for vaccine information-seeking behaviour and vaccine information scanning. These variables were found to play a role in information channels and sources selection, indicating individual differences in access and use of particular sources of information.

Keywords: *Vaccine; Immunisation; Information seeking; Information scanning; Decision-making*

3.2 Introduction

Mass-vaccination is second only to clean water in reducing the global burden of infectious diseases (140). When vaccinations are widely available and convenient, the vast majority of people follow the recommended vaccination schedule (141,142). However, there are some individuals that choose to delay, to partially vaccinate with certain vaccines, or refuse vaccination (66). If many people delay or refuse vaccination within a community this may ultimately lead to low vaccination uptake and the resurgence of infectious diseases (143–146).

When a healthcare professional prompts vaccination, most individuals vaccinate automatically, with only a small minority actively weighing up the pros and cons of such a medical intervention (147). Occasionally, however, individuals supplement, or disregard entirely, the official information on vaccination provided by a healthcare system and inform their vaccine decision in accordance to information that they have been passively exposed to during their everyday life, or actively seek from additional sources. If such information is trusted and critical of vaccination, this may subsequently influence an individual away from vaccination (148,149).

A range of information practices have been recognised as important factors in health decision making (32–34,38). Here, we focus on *health information-seeking behaviour* and *health information scanning*, two information practices wherein individuals may acquire information for use during a healthcare decision such as vaccination. Health information seeking behaviour refers to verbal and non-verbal behaviours that can be used to attain, clarify, or confirm information (32). Whereas, health information scanning involves the incidental exposure, attention to and retention of information throughout the course of an individual's everyday life (150–152).

These health information practices involve the utilisation of a range of *information channels* that facilitate the transfer of information. For instance, information channels may include the internet, interpersonal contacts or the print media. Within each information channel, a range of health related *sources* originate *messages* that communicate different health information (153). Information sources under this definition would be organisations such as the NHS, individual family members or specific publications such as The Daily Mail.

Sources can communicate through a number of different channels, for example, the NHS may communicate a message in person through a GP, through the internet and through the TV news. Messages may stay relatively consistent within sources (e.g. the NHS pro-vaccination messaging related to the HPV vaccine) or may be subject to change over time (e.g. the NHS messaging related to dieting and nutrition).

According to Johnson, Andrews & Allard (40), an individual's beliefs, attitudes and intentions influence the choice of channels and the selection of sources that an individual may use for information (40), this in turn influences the messages an individual is likely to receive and ultimately the information which may inform a decision. Johnson & Case (33) refer to the outcome of this process as an individual's *information field*, a particular assortment of

preferred channels and sources of information that is unique to each individual and which provides the basis for health information-seeking and scanning to occur (33,40). In regards to information about vaccines, vaccinators and non-vaccinators frequently report a range of preferred information channels and sources.

While a great deal of research has focused on the content and influence (21,154–156) of vaccine messages, little is known about the information practices which may determine whether such information is easily accessible and available, and how likely such information is to inform real world vaccine decision-making. A further understanding of the information practices leading to channel, source selection and their impact on the subsequent vaccine decision-making process may prove beneficial to future vaccine communication strategies.

The aims of this systematic review are:

1. To review the prevalence of vaccine information-seeking behaviour and vaccine information scanning across human vaccination programmes.
2. To identify a range of antecedents to vaccine information-seeking behaviour and vaccine information scanning.
3. To examine vaccine information channel and source selection and their possible interaction with antecedents to vaccine information-seeking behaviour and vaccine information scanning.
4. To examine the possible effects of vaccine information-seeking behaviour and vaccine information scanning on the vaccine decision-making process and vaccine uptake.

3.3 Method

3.3.1 Search strategy

A systematic review was conducted across several multidisciplinary databases including: Medline, PubMed, Psychinfo, Cochrane, Web of Science, EMBASE, and IBSS. The search took place between 02/11/2017 and 09/11/2017. See Table 5 for the Boolean search term used.

Keywords used in search strategy.

Vaccin\$ OR immunis\$ OR immuniz\$
AND
information seek\$ OR information search\$ OR
information gather\$ OR information find\$ OR
information scan\$ OR knowledge seek\$ OR
knowledge search\$ OR knowledge gather\$ OR
knowledge find\$ OR knowledge scan\$

Additional limits

- 1970-2018
 - Peer review journal articles
 - Original research
 - English language
-

Table 5: Boolean search term used for review

The abstracts were read of those articles whose titles indicated the examination of participants vaccine decision making process. The entire article was read if the abstract indicated the active or passive accumulation of information or knowledge as an area of investigation within the study, or the study referred to any of the following: (i) Information-seeking behaviour (ii) Information scanning (iii) Sources or channels of information. References and bibliographic lists of all of these articles were also examined.

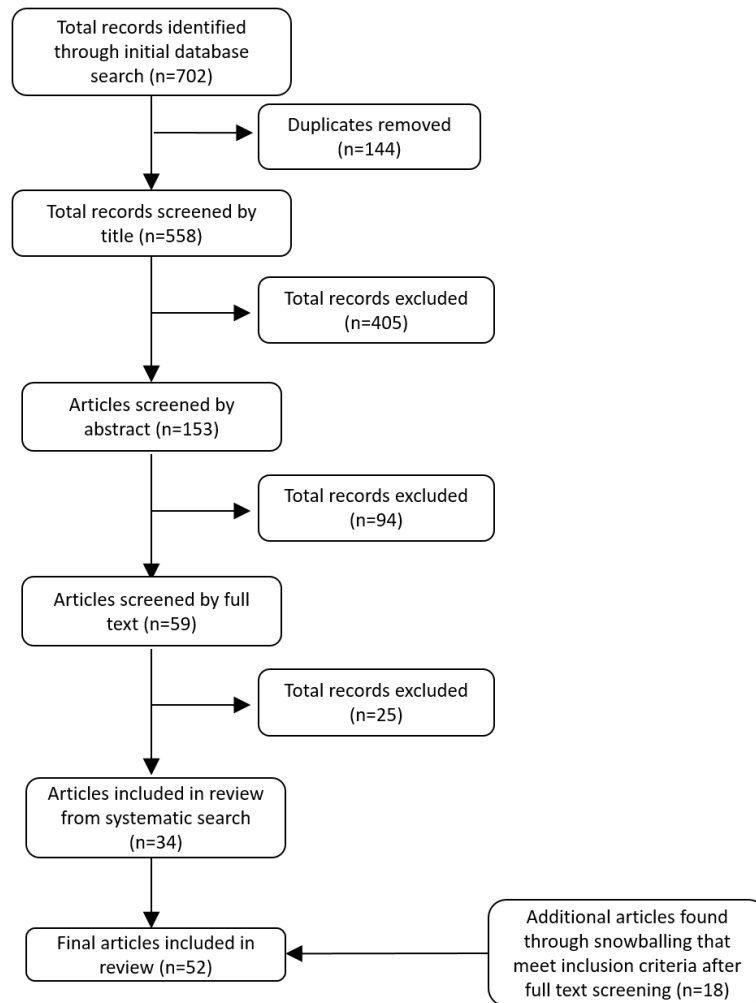


Figure 4: Search flow diagram

3.3.2 Eligibility Criteria

In order to be included in this review the study must have collected quantitative or qualitative data from, or in regards to, parents, health care workers or individuals making a decision or having made a decision about a vaccine for their child or themselves. Any country of investigation was permitted so long as the final study was written in English and published in a peer review journal. Vaccine type was limited to any childhood, adult or maternal vaccine intended for human use (i.e. excluding animal vaccination).

Studies that examined travel vaccines were excluded, so as to focus the review exclusively on vaccines that are available and recommended within a participant's country of residence.

Health care professionals also occasionally seek information in regards to vaccines for professional reasons. Studies with this focus were excluded in order to keep the review focused on the vaccine decision making process of the individual for which the vaccine is intended, or their child. The search and eligibility criteria were confirmed by all authors.

3.3.3 Data Extraction

After screening 34 articles were found to meet the inclusion criteria. From these an additional 18 articles were found through snowballing and additional searching. In total, 52 studies were included in the review (see figure 4). Data was extracted by one author (RC) using an excel database created specifically for this process. The data extracted included: country of focus (separated by state, city or region, if such information was included), population, sample size, vaccine(s) of focus, study design, aspect of vaccine decision making, definition of channels and sources of information, and the study's main vaccine information related findings.

The vaccine information related findings were categorised into those findings related to: (1) Prevalence and extent of vaccine information-seeking behaviour and vaccine information scanning. (2) Antecedents and cited reason for vaccine information-seeking behaviour. (3) Consequences of vaccine information-seeking behaviour. (4) Antecedents of vaccine information channel and source selection. (5) Consequences of vaccine information channel and source section. Percentages, odds ratios and *p*-values were extracted for each where appropriate. Where multiple studies recorded similar statistics, as was the case for percentage of individuals that sought out additional information, an average was calculated as weighted by study sample size. Not all studies reported findings on each of these categories, however, all studies had findings contributing to at least one category. No formal extraction of qualitative findings was conducted, these studies were read and used to illuminate and supplement the quantitative findings.

3.3.4 Quality and risk of bias

No formal assessment of study quality or risk of bias were conducted for this review.

Subjectively all studies included were thought to be of good quality. A risk of bias, however, may have been present across studies whereby only studies with particularly noteworthy results related to vaccine information were reported and, as such, given prominence within the studies abstract. Studies whose author's thought the variable played a minor role were therefore likely systematically missed from this review.

3.4 Results

3.4.1 Characteristics of studies

3.4.1.1 Location

Of the 52 studies included in the review 29 studies were based in the USA and Canada (across 16 states) (46,106,157–183), 10 studies were based within the European region (14,48,147,184–190), two studies were based in Israel (191,192), three studies were based in South Korea (193–195), three studies were based in Australia (196–198), one study was based in China (199), and four studies did not restrict by country (200–203).

3.4.1.2 Study design

Of the studies 28 were cross-sectional survey studies (48, 59, 106, 157-159, 161-164, 168, 170, 171, 173, 176, 177, 179, 180, 184-186, 188, 193-195, 198, 199), 12 studies were qualitative in nature (either focus groups or individual in-depth interviews) (14, 46, 165, 172, 178, 181, 187, 189, 190, 191, 197, 203), 11 studies were media monitoring, search engine or social media analysis (160, 169, 174, 175, 182, 183, 192, 196, 200, 201, 202) and one study was experimental (167).

3.4.1.3 Vaccine of focus

The majority of studies either focused on childhood vaccination in general or individual specific vaccines. These included 16 studies on childhood vaccines (147,158,165,168,171–

173,176,178,179,181,182,185,188,194,196), 13 studies on the HPV vaccine (106,157,162–164,166,174,177,183,189,190,195,202), six studies on the seasonal influenza vaccine (161,167,180,184,193,199), five studies on the H1N1 influenza vaccine (46,48,159,186,198), five studies on the MMR vaccine (14,169,187,197,201) and two on the polio vaccine (191,192). Three studies focused on vaccination in general (175,200,203). One study focused on both the H1N1 influenza and HPV vaccines (160) and one on general maternal vaccination (170).

3.4.1.4 Element of vaccine information behaviour

Each study touched on a different aspect, or aspects, of vaccine information seeking and scanning behaviour and the channels/sources used. Fifteen studies examined the prevalence of vaccine information scanning and seeking behaviour (48,106,147,157–159,161,166,173,179,186–188,199). Seventeen focused on the predictors and reported reasons for vaccine information seeking behaviour and vaccine information scanning (14,46,157,158,162,166,168,171,177,180–182,186,188,190,196,202). Eight studies indicated the potential impact of vaccine information-seeking behaviour and scanning (48,106,161,164,166,179,186,199).

Nineteen studies looked at the prevalence of sources used (48,106,147,157–159,161,168,170,173,176,177,179,180,183,186,188,190,195), 12 studies looked at predictors of these sources (48,157,158,165,170,175,178,181,186,190,198) and 13 studies looked at the possible impact of using such sources/channels (48,158–160,167,168,173,176,181,184,189,191,197).

3.4.2 Prevalence and extent of vaccine information-seeking behaviour and information scanning

The proportion of individuals that actively engage in vaccine information-seeking behaviour ranges from 25% (166) to 94.3% (48) of a sample (see Figure 5). The proportion of

individuals who are found to seek information about vaccination varied across 11 studies (48,106,159,161,166,168,173,179,186,188,199). Figure 5 shows the reported search behaviour across studies with the inclusion of a weighted average (proportionally weighted by sample size) for each vaccine (or vaccine type) of interest. The HPV vaccine and the seasonal influenza vaccination for healthcare professionals had a similar weighted average of participants actively searching for information with 26% and 31% respectively. For the studies that examined childhood vaccinations a weighted average of 47% of participants actively searched for information. The H1N1 influenza vaccine was associated with the most searching for information, with a weighted average of 82% of participants actively searching for information about the vaccination.

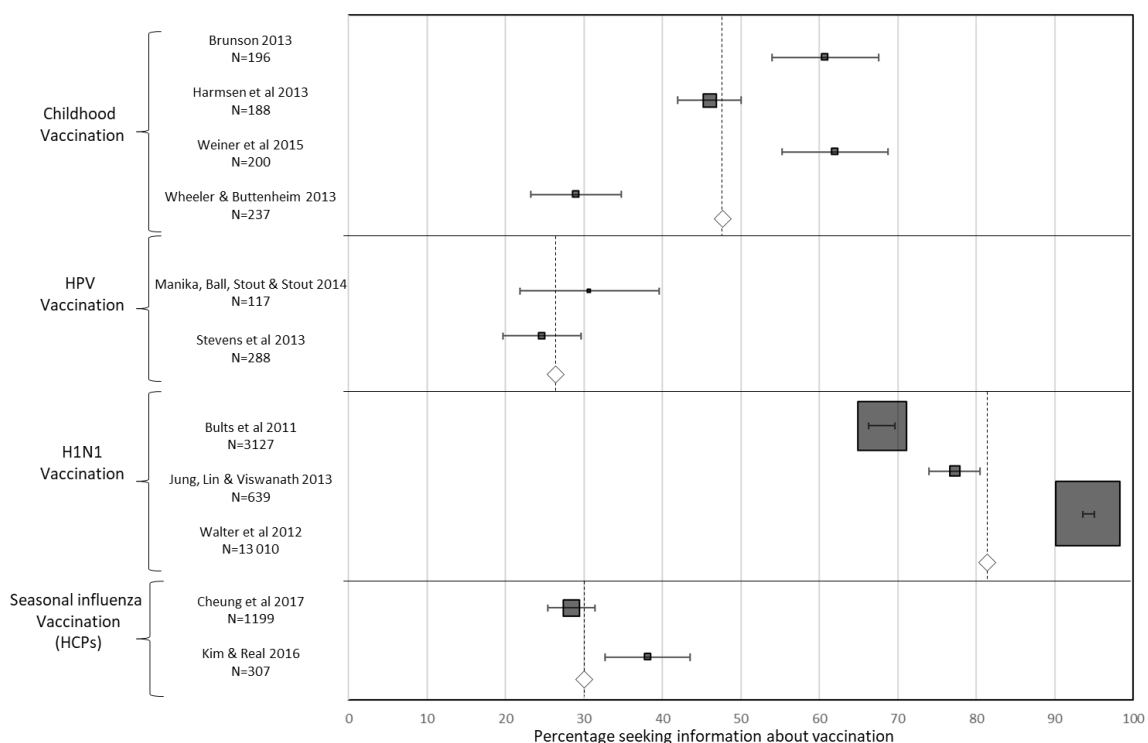


Figure 5: Percentage of individuals actively seeking information about vaccination per study and across vaccine type. *The size of the box represents the relative size of each study. The centre point of each indicates the percentage of participants who sought information*

about vaccination, with a 95% confidence interval. The diamond and dotted lines indicate the weighted-average fixed-effect for each vaccine or vaccine type.

Three studies reported the number of sources individuals sought out when seeking information about vaccination (158,173,199). Cheung et al (199) indicated that 9% of individuals actively sought additional information about the seasonal flu vaccines from two or more sources, while Wheeler & Bутtenheim (173) and Jones et al (158) reported 29% and 95.6% of parents, respectively, used information from two or more sources to inform their childhood vaccination decisions. In Jones et al's (158) study, 16% of their sample obtain information about vaccines from seven or more sources of information (158).

Few studies quantitatively investigated vaccine information scanning (the passive acquisition of vaccine information). Stevens et al (166) measured the concept in regards to participants having noticed information about the HPV vaccine through various information channels. They showed that scanning of vaccination information occurred with 75.7% of participants surveyed. This is similar to the findings of Hughes et al (157) who found that 83% of their participants had heard about the HPV vaccine through at least one information source.

The only other studies within our review that examined this aspect were Cheung et al (199) and Campbell et al (147). Cheung et al (199) reported that 98% of healthcare professionals passively received one or more items of information in regards to their own seasonal influenza vaccinations. Campbell et al (147) asked if parents had "seen, heard or read anything about immunisation for children in the last 12 months", 53% confirmed that they had.

The extent of vaccine information seeking and scanning was also mentioned within the reviewed qualitative literature. For instance, Fadda Galimberti, Carraro & Schulz (187) noted that half of their participants described themselves as active information seekers who try to

consult as many sources as possible when making a vaccine decision (187). Benin et al (178) suggests that mothers prefer to conduct this active search behaviour for vaccine information during their pregnancy to prepare for upcoming childhood vaccination decisions once their child is born. For parents hesitant of vaccination Benin et al (178) goes on to suggest that this searching process may be extensive and involve a lengthy period of time asking question in consultations with their health care professional (178).

In regards to vaccine information scanning, Boyd & Gazmararian (46) describe how their interviewees mentioned a news clip of a cheerleader, presumably suffering negative effects from the H1N1 vaccine, that “went viral” during the outbreak. Participants cited this clip as evidence of inadequate safety research related to the vaccine. Further to this, they also mention ineffective dissemination of information from the healthcare system and the unavoidableness of scanning fear inducing information from television sources. Research by Bragazzi et al (200) supplements this finding by demonstrating that internet search queries for vaccinations increased dramatically during the 2009 H1N1 influenza outbreak and suggest a relationship between scanning such information through broadcast media and subsequent active seeking of vaccine information.

3.4.3 Antecedents and cited reason for vaccine information seeking behaviour and vaccine information scanning

We found three sets of vaccine information seeking and scanning antecedent variables in the reviewed literature: (i) socio-demographic antecedents (e.g. ethnicity, native language, level of education and age), (ii) social-cognitive antecedents (e.g. trust, risk perception and attitude) and (iii) contextual factors related to information seeking.

3.4.3.1 *Socio-demographic antecedent variables of vaccine information-seeking behaviour*

Five of the studies reviewed found evidence for a range of socio-demographic factors that precede vaccine information seeking or vaccine information scanning.

Being of Black (OR, 0.43; 95% CI, 0.19–0.97) or Hispanic (OR, 0.39; 95% CI, 0.16–0.97) ethnicity, compared to being of non-Hispanic White ethnicity, predicted lower levels of vaccine information-seeking behaviour related to the HPV vaccine (177). Similar findings were also apparent for information scanning related to the HPV vaccine. Results from a survey conducted by Hughes et al (157) found African American participants were significantly less likely to have heard about the HPV vaccine from advertisements than Whites, while Stevens et al (166) indicates that English speakers reported more HPV information scanning and active information seeking than Spanish speakers in the US (166).

In Bults et al's (186) study related to the H1N1 vaccine, higher education levels predicted a higher likelihood to seek information about the H1N1 vaccine (186). Harmsen et al (188) also found this effect for parents seeking information about childhood vaccines (OR, 1.23; 95% CI, 1.10–1.38).

3.4.3.2 Socio-cognitive antecedent variables of vaccine information seeking behaviour

Three studies identified socio-cognitive factors related to vaccine information-seeking behaviour.

Harmsen et al (188) and Clarke & McComas (180) both investigated vaccine information-seeking behaviour in terms of the common factors within the Theory of Planned Behaviour (attitude, norms and perceived behavioural control)(204). Both studies found a relationship between attitude and social norms towards information-seeking behaviour and vaccine information seeking-behaviour. However, neither of the studies found a significant relationship between perceived-control/self-efficacy related to the behaviour and vaccine information-seeking behaviour itself.

McKeever et al (171) examined factors of communicative action (sharing, actively seeking and attending to information) related to childhood vaccination (for instance, sharing a vaccine critical article on social media). They found that the more supportive mothers were about

vaccination the less likely they were to engage in communicative action, and that the higher the level of affect involvement (i.e. emotion felt towards vaccination) felt by the participants the more likely they were to engage in communicative actions (171).

In two studies, a tendency for conformation of previously held beliefs was evident. In both Dunn et al (202) and Getman et al (182), participants that held anti-vaccination beliefs were seen to prefer and interact with anti-vaccination information while those with pro-vaccination beliefs are seen to prefer and interact with pro-vaccination information (182,202). These findings are similar to the echo chamber effect found by Schmidt, Zollo, Scala, Betsch & Quattrociocchi (203).

3.4.3.3 Contextual factors related to vaccine information-seeking behaviour

Three studies found contextual factors related to vaccine information-seeking behaviour.

Jones et al (158) found that having a child with a nonmedical exemption to vaccination predicted an increased level of vaccine information-seeking behaviour. Mayne et al (162) and Ward et al (190) suggest that receiving a reminder prompt from a health care professional and scanning threatening information online, respectively, related to seeking out additional information about vaccination.

3.4.3.4 Explicitly stated reasons for vaccine information seeking behaviour

Further to the above antecedents, eight studies reported individuals explicitly stated purpose behind their seeking additional information about vaccination. Reasoning here revolved around two identifiable themes. First, a perceived information deficit, uncertainty and resulting need for information (46,181,196). Second, a social desirability to seek information and to remain informed about vaccination (14,168,180,188). All of which were cited as reasons for seeking information about vaccination.

3.4.4 Potential impact of vaccine information seeking behaviour

Vaccine information-seeking behaviour and vaccine information scanning is present in individuals that vaccinate and in those that are hesitant, delay or refuse vaccination. Six

studies recorded both vaccination uptake and vaccine information-seeking behaviour. Non-vaccinators in two studies (179,186), searched for vaccine information at a higher rate than vaccinators. While in the remaining four studies, vaccinators searched for vaccine information at a higher rate than non-vaccinations (48,106,161,199).

From these findings, healthcare professionals that actively searched for information about their own seasonal influenza vaccine have a significantly higher likelihood of belonging to the group that opted to be vaccinated (161,199). Similar findings were suggested for the HPV vaccine, whereby vaccine information seeking related to a significantly higher likelihood of accepting the vaccine (163).

Actively searching for additional information, however, was also occasionally found to relate to a lower vaccination uptake rate. In Brunson et al (179) 26% of vaccinators sought out information about the childhood vaccination program compared to 40% of non-vaccinators and in results presented by Bults et al (186) information was sought out in 76% of non-vaccinators and 56% of vaccinators.

Additional findings attempt to explain this negative relationship by suggesting that when a high level of conflicting information is gathered, frustration related to information overload can occur (172). At this point individuals can either become dejected (46) or continue searching and may follow suggestions to select or delay vaccination according to an alternative schedule in an attempted compromise (172).

This quote from a participant that selectively vaccinated their child in Sobo et al's 2016 study (165), demonstrates a thought process behind this type of behaviour.

"I'm always doing more research, I never am settling for what I've decided upon thus far... It's not a decision that it's just very black and white and once it's made it's made, it's very fluid, and definitely the hardest decision I've ever made, and is—yeah, it's just always being

researched, it's always in—something in the back of my mind that I'm thinking of at all times [laughs].” (165)(p.537)

3.4.5 Vaccine information channel and source usage

Twenty studies recorded where participants received their vaccine information. Of the 20 studies, three (161,180,183) made a distinction between channel of information (the means through which information is passed) and information source (the specific originator of the information), the remaining 17 studies referred to all related measured aspects as sources.

The specific terms used within questions to investigate channels/sources differed widely across studies, however these can often be divided into seven main categories: Healthcare Professionals (HCPs), the Healthcare System (HCS), Print Media, Broadcast Media, Academic Media, The Internet, and Interpersonal Contacts (not including HCPs). The different ways in which these are referred to across all 20 studies are listed in the supplemental materials (Appendix C).

Fourteen studies investigated participants use of either a channel or source of information, four studies investigated levels of trust in, or perception towards, information channels or specific sources (106,147,176,198), one study asked participants to rate their preferred channels of information (161) and one study assessed source credibility (180).

Channel and source usage differed greatly across vaccine(s) of investigation. Figure 7 presents the weighted average percentage of usage across the 14 studies (General childhood vaccination: five studies (158,168,173,179,188). General maternal vaccination: one study (170). H1N1 influenza vaccine: three studies(48,159,186). HPV vaccine: five studies (106,157,177,183,195). Note: not all studies presented all channels/sources as options for use).

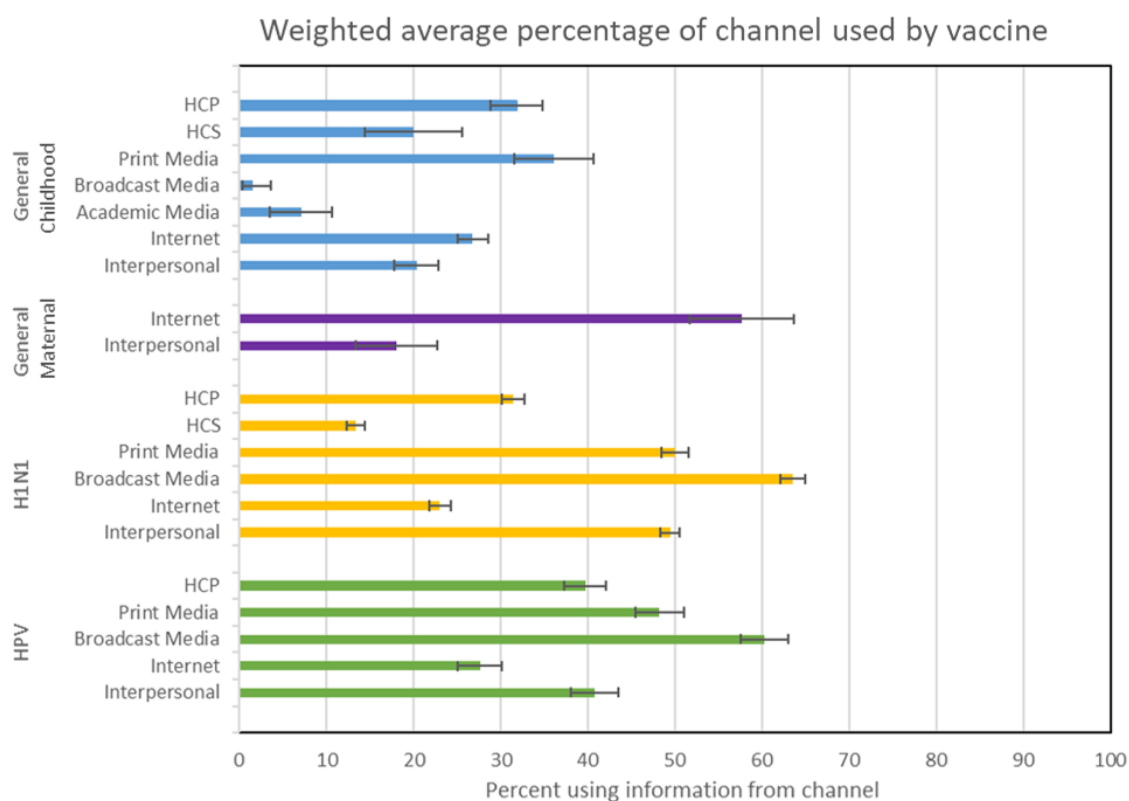


Figure 6: Average weighted percentage use of information channel across vaccination type. The bar chart presents the weighted-averages (with 95% confidence intervals) of 14 studies that measure participant channel and source use within their study. Separate averages have been presented for each vaccine and vaccine type.

3.4.6 Predictors and preferences of channel and source use

Socio-demographic factors and a relationship of trust in an individual's health care

professional were the overriding predictors for channels/sources used when gathering vaccine information.

3.4.6.1 Socio-demographic factors and source selection

Jones et al (158) found that a higher education level predicts internet use for information

about the childhood vaccination. This finding was similar to that of Ellingson & Chamberlain

(170) who found that women with a bachelor's degree were around 3.5 times more likely to

use the CDC website to obtain information about maternal vaccination than women without a

degree (OR, 3.46; 95% CI, 2.21–5.43). In a separate study, which focused on the childhood

influenza vaccination, parents with a university education were also less likely to trust complementary and alternative medicine (CAM) practitioners than parents without a university education (61% vs 76%, OR, 0.5; 95% CI, 0.3–0.9) (198).

Race and country of origin formed another social demographic factor that interacted with channel/source usage. For example, African Americans were found less likely than Whites to have heard about the HPV vaccine from advertisements but more likely to have heard about it from a broadcast source (157). In a similar finding to that of educational status, Ellingson & Chamberlain (170) found that white women were 4 times more likely to use the CDC website to obtain information compared to African-American women (OR, 4.21; 95% CI, 2.61–6.77). Further to these findings, Bults et al (186) found that immigrants to Holland were significantly more likely to seek information from their friends and family members about the H1N1 vaccine than native Dutch individuals (186).

Age did not appear to factor into parents' source selection choices when making a decision about their children's vaccinations (170,198). However, it did have an influence for those individuals over 60 years of age in regards to their own H1N1 vaccine decision (48), with this older demography being significantly less likely to use the internet for information and instead obtained information more frequently from conventional media sources such as radio, television, newspapers, and magazines.

3.4.6.2 Trust and its influence on channel use and source selection

A higher level of trust in an individual's health care professional can reduce the amount of information that a parent feels they need to make a decision (178), and reduce the extent to which individuals are likely to seek information from other sources (158,175). This inhibiting effect on the behaviour is illustrated in the qualitative work of Sobo et al (165) by the following quote from a participant explaining their vaccine decision-making process:

“Well I take her to the pediatrics [sic] and I trust that they know what they’re doing and . . . [pause] I don’t know what else to say [laughs].” (165)(p. 533)

The inverse can be seen documented in a study by Ward et al (190) whereby a participant talks of *“changing her family doctor to ensure a more ‘natural’ less medicalised approach”* (190)(p.49) after they became disappointed in their previous paediatrician. Also in the occasions where health care professionals are highly trusted, if access is restricted a source from the internet may be used due to its higher level of convenience (181).

3.4.7 Potential impact of channel/source selection

The impact of three channels of information were examined in-depth across the reviewed studies; health care professionals, the internet and broadcast media.

3.4.7.1 Health care professionals

The main finding of note across the studies was the positive effect that receiving information from a health care professionals has on attitude and uptake of vaccination. As findings from Wheeler & Bittenheim (173) demonstrate, parents who reported getting vaccine information from their doctor were 7 times more likely to have no immunisation concerns than those that did not (aOR 7.09, $p < 0.001$). The use of a healthcare professional as a source of information in turn lead to an 80% lower odds of the parents in the study intending to follow an alternative immunisation schedule (aOR 0.19, $p < 0.05$) (173).

A similar finding was also evident in the study conducted by Walter et al (48), who found a significant association between vaccine uptake and seeking vaccine information from physicians (OR, 2.77; 95% CI, 2.16–3.57) or official materials (OR, 2.07; 95% CI, 1.55–2.77) as a main source of information. Those within a vulnerable target population were significantly more likely to report using a healthcare professional as a source of information, and for those who vaccinated, a healthcare professional had been used as a source of information 62.1% of the time (48).

Further to this finding, Greenberg, Dubé & Driedger (176) showed that vaccine acceptors reported trust in a healthcare professional as a source of information at substantially higher rates than non-vaccinators.

3.4.7.2 The internet

Results from a 2002 survey of online vaccine information usage published by Jones et al (158) compared parents that used the internet for vaccine related information and those that did not. Those that cited using the internet for vaccine information were more likely to have a child with an exemption to at least one vaccine (OR, 3.53; 95% CI, 2.61–4.76), were more likely to think that the National Vaccine Information Center (a US based anti-vaccine organisation) and CAM providers were a good source of information (aOR, 1.69; 95% CI, 1.12–2.55 and aOR, 1.55; 95% CI, 1.12–2.14 respectively), were less likely to consider official sources as good sources of information and were more likely to hold beliefs about vaccination that are not supported by the scientific research (158).

In a 2015 study by Weiner et al (168), the internet was frequently cited as a top source of childhood vaccination information. When uptake was examined, significantly more participants that delayed or declined childhood vaccination (58.6%), as compared to acceptors (32.7%), cited the internet as one of their top three sources of information.

Conversely, in a large-scale study of internet search behaviour and uptake, Kalichman & Kegler (160) found that the volume of internet searches regarding both the H1N1 and HPV vaccines significantly correlated with vaccine uptake (160), indicating a possible positive effect of internet based vaccine information-seeking behaviour on vaccine uptake.

Some of the studies suggested that misleading information can be found online when information seeking is undertaken in an “unskilled manner”. For instance Agree, King, Castro, Wiley & Lg (167) demonstrated that worse initial health literacy leads to lower quality and potentially misleading health information being found during an internet vaccine

information seeking task. Downs, de Bruin & Fischhoff (181) further support this by suggesting that those most likely to be at risk of being influenced by misinformation were also those that were most likely to use simplistic search terms related to vaccination and subsequently increase their likelihood of reaching anti-vaccine websites (205,206). Betsch & Wicker (184) suggest that even when medical students were to search for vaccination information online, searching conducted with their provided search terms lead to “anti-vaccination websites” 11% of the time.

Within social media specifically, three studies investigated information seeking and communication in open forum groups (189,191,197). Debate within these groups are often highly emotive and frequently involve narratives of personal experience with vaccination (197). All three studies mention the importance of health care professionals actively engaging within these groups to improve the accuracy of messages received through such channels when questions pertaining to vaccination are asked in good faith (189,191,197).

3.4.7.3 Broadcast media

When television or radio were classified as a main source of information in regards to the H1N1 vaccine uptake was significantly lower (OR, 0.62; 95% CI, 2.16–3.57) (48). Jung, Lin & Viswanath (159) examined television in more depth and indicated that the use of local television news related to substantially lower H1N1 knowledge than cable TV (aOR, 11.30; 95% CI, 2.46–51.87), news and the internet (aOR, 15.13; 95% CI, 4.72–48.54). Uptake of the H1N1 vaccine within this study was significantly more likely if national television and non-English television were used for vaccine information as compared to local television news (aOR, 2.95; 95% CI, 1.18–7.37 and aOR, 10.83; 95% CI, 1.53–76.71, respectively) (159).

3.5 Discussion

The studies gathered here illustrate that a sizeable proportion of individuals search or are exposed to information regarding vaccination. Information gathering through the means of

either vaccine information-seeking behaviour or vaccine information scanning can frequently take place outside the context of a consultation with a healthcare professional (179). As such, the argument that these information behaviours place people at risk of being exposed to information that is confusing, unreliable or actively misleading is understandable. While this is certainly a possibility, the findings presented here indicate that even though a large number of people search for vaccine information the majority of those that do so subsequently proceed to vaccinate.

Not only is seeking information infrequently a threat to vaccine uptake it appears that the seeking behaviour can actively increase uptake. This is demonstrated in significantly higher levels of vaccine information seeking reported in healthcare professionals accepting the seasonal influenza vaccination (161,199) and in similar results regarding young adults and the HPV vaccine (106).

The process of vaccine information seeking can be problematic when it is conducted in an unskilled manner (167) or with the purpose of confirming a previously held negative attitude towards vaccination (169,182). Furthermore, as Downs, de Bruin and Fishhoff argue, those with the greatest need to know more about vaccination seem to be the most vulnerable to being confused by the information that they find (181).

3.5.1 The Vaccine Information Field

How likely someone is to gather information from a particular information channel, and sources within that channel, differs across demographic, attitudinal and situational factors.

Not only does non-White ethnicity appear to be associated with less overall vaccine information seeking behaviour (177) and a lower likelihood of having scanned information related to the HPV vaccine (157) it also relates to individuals being more likely to seek information from friends and family members (186). A similar relationship exists in regards to educational attainment. The higher an individual's level of education the more likely they

are to seek information (186,188) and the more likely they are to seek information through the internet (158).

This selection and preference of channels, and sources within those channels, reflects Johnson & Case's notion of the *information field* (33). Individuals are often limited in the range of sources that are available, or that they choose, to use to inform their decision-making. As such, decisions are often based on an incomplete picture of the information landscape. Demographic, contextual and socio-cognitive factors shape the likelihood that a particular channel/source will be used. Educational interventions would therefore benefit from a greater awareness of the specific information field that their target populations are most likely to draw from so as to target official messages effectively.

Furthermore, it is important to acknowledge individuals as active agents that curate their own information field (33). In this way, a successful communication strategy for vaccination during pregnancy, for example, may have the added benefit of shifting an individual's information field so that a future decision about childhood vaccination is based on information that is more reliable.

3.5.2 Strengths and limitations

The scope of this review limited the studies collected only to those that explicitly stated the preference, use of and trust in vaccine information. As such, studies where information was thought, by their authors, to play a minor or inconsequential role were not included. A lack of these studies may have introduced bias into this review. Furthermore, in order to narrow down the literature a restrictive search strategy was employed. A more open search strategy that focused on decision making and then narrowed down based on the information criteria may have yielded additional papers for this review.

This study attempts to investigate a topic that, as of yet, has not been thoroughly defined as such measurement of some concepts across the reviewed studies varied greatly (as can be

seen in table 2 of the supplemental materials in Appendix C). As such, any meta-analysis of such studies was problematic. As for the qualitative research, no formal methodology was used to summarise these findings and as such they are only used to give additional depth to the quantitative findings.

The protocol for this study was not registered on the PROSPERO database or other systematic review registration database.

3.6 Conclusion:

This review demonstrates that a high proportion of both those that vaccinated and those that refuse a vaccine search for information about vaccination. The seeking of such information from trusted official sources (e.g. a healthcare professional) substantially improves the likelihood of vaccination. Differences in demographic, situational and socio-cognitive factors guide individual to seek, and be passively exposed to, information from different sources. A better understanding of differing vaccine information fields would be beneficial to determine how educational campaigns can best be targeted in the future.

RESEARCH PAPER COVER SHEET

PLEASE NOTE THAT A COVER SHEET MUST BE COMPLETED FOR EACH RESEARCH PAPER INCLUDED IN A THESIS.

SECTION A – Student Details

Student	Mr Richard M Clarke
Principal Supervisor	Dr Pauline Paterson
Thesis Title	Vaccine information-seeking behaviour: its predictors and influence on vaccination during pregnancy

If the Research Paper has previously been published please complete Section B, if not please move to Section C

SECTION B – Paper already published

Where was the work published?	Vaccine		
When was the work published?	May 2019		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	No	Was the work subject to academic peer review?	Yes

**If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.*

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	
Stage of publication	Choose an item.

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)

I designed the studies, collected the data, conducted the analyses and wrote the manuscript. Dr Pauline Paterson and Dr Miroslav Sirota supervised and gave regular feedback during this process and confirmed the work before submission.

Student Signature: _____

Date: _____

Supervisor Signature: _____

Date: _____

4. Determinants of satisfaction with information and additional information-seeking behaviour for the pertussis vaccination given during pregnancy

4.1 Abstract

Objectives: Information search and processing is critical to the vaccine decision-making process. However, the role of drivers of information satisfaction and search is not fully understood. Here, we investigated the predictive potential of psychosocial characteristics related to satisfaction with information and additional information-seeking about the pertussis vaccine currently recommended during pregnancy.

Design: Cross-sectional online questionnaire study.

Methods: A UK based sample of 314 women who had given birth during the previous six months was recruited to participate. The questionnaire included measures of the psychosocial predictors: *trust, coping strategies, attitude towards vaccine information-seeking behaviour* and *risk perception of vaccination during pregnancy*, and measures of two outcome variables: *satisfaction with information* received from a healthcare professional and whether participants engaged in *vaccine information-seeking behaviour*.

Results: Trust in healthcare professionals, a perceived behavioural control of own vaccine information-seeking behaviour, and an engaged problem-focused strategy for coping with stress were significant predictors of satisfaction with official information given by a healthcare professional. 40% of women sought out additional information about vaccination however, none of the psychosocial factors measured significantly predicted the behaviour.

Conclusions: We found that high trust in healthcare professionals, a perceived ability to seek out accurate information about vaccines and actively focusing on problems as a means of coping with stress, drives satisfaction in official vaccine information. We also developed measures of these variables that could be used in further research.

4.2 Introduction

When making a decision about childhood vaccination, parents frequently prefer, trust and use healthcare professionals as a source of information (106,158,170,175,184,185,190,198).

Occasionally, due to unsatisfied information needs, additional sources of information are actively sought out (50,207). This seeking can take place across numerous sources (158,190) and, for some individuals, can be an extensive process (168) that is highly influential in their final decision (74). When vaccine information-seeking behaviour occurs, information from sources is assessed, trusted, and perceived as influential to varying degrees across different individual decision makers (48,158,208–210). Although vaccine information-seeking behaviour is present in individuals who both accept and refuse vaccination (106,169,186), the behaviour poses a potential risk factor for exposure to information that is misleading and unduly critical of vaccination (22,24,29). This information can be influential in the forming of knowledge, attitude towards, and final uptake of a vaccination (148,211–213)

4.2.1 The pertussis vaccination program

The recommendation that pregnant women receive a pertussis (also known as whooping cough) containing vaccination during the course of their pregnancy was initially introduced as a response to a particularly widespread outbreak of the disease in early 2012 which led to the death of 14 infants. This vaccination programme has now become a staple of the standard UK immunisation schedule (53). Prior to this vaccination programme, immunity from pertussis, across the UK, was achieved through regular childhood vaccination using the 5 in 1 tdap vaccination, however, even with high coverage rate in children (>95%) the 2012 outbreak of the disease still occurred (54). Safety and efficacy research (55-57) suggest that the addition of the same vaccine during pregnancy was justified and consequently mothers between 16 and 36 weeks of pregnancy are now currently recommended the vaccine.

Vaccination during this time period, offer mothers protection from pertussis whilst passing on

temporary protection to their baby until they are old enough to receive the regularly scheduled childhood version of the vaccine (58).

Previous research involving pregnant and recently pregnant women demonstrates a strong willingness to vaccinate against pertussis during pregnancy. For example a UK based survey conducted in January 2013 (three months after the introduction of the pertussis vaccination during pregnancy) Campbell et al (59) found that 94% of respondents indicated that they would either 'definitely' or 'probably would' accept a vaccine during pregnancy offered by their GP or midwife, an intention that has not yet, however, been reflected in the yearly uptake which currently stands at approximately 68% (215).

This uptake is likely partly due to a number of situational factors in regards to this particular vaccination program. For example, for the first 3 years of the programme midwives not having the correct Patient Group Directions (PGDs) in place to offer the vaccine during their consultations, meaning that women would have to set up an additional consultation with a GP in order to receive the vaccination. Furthermore, when the PGD allowing midwives to deliver the vaccine was later put into place the lack of self-efficacy in giving advice about the new vaccine may have presented a barrier to them giving a strong recommendation in regards to the vaccine.

A related factor to recommendation is the communication of vaccine related information within consultations. A London focused survey of pregnant women (N=200) proposes information needs as a significant barrier to uptake of the pertussis vaccine (65). Uptake of the pertussis vaccine during pregnancy was low in this study with only 26% of women vaccinating during their pregnancies. Of the women that had not vaccinated during their pregnancy 51.3% indicated that they were not aware of the vaccination program and 32.6% cited that they did not vaccinate due to a lack of information to make the decision.

Furthermore, the vast majority (91%) of all women in the study believed that their Health care professional should have provided additional, detailed information about vaccination during pregnancy.

The Campbell et al. study (N=638) also examined information needs of the women that were offered the pertussis vaccine. Of these women 69.7% reported that they had received enough information for them to make their decision while 21.3% felt they had some but would have wanted more information and 8.9% either had none or not enough information. These finding point towards a perceived information deficit in approximately a quarter of individuals making their decisions to vaccinate for pertussis during pregnancy.

4.2.2 Vaccine information-seeking behaviour during pregnancy

Information-seeking behaviour for a wide range of health related reasons is common during pregnancy (51,60,217–221). In relation to vaccine specific information-seeking behaviour in pregnancy, Bodeker, Walter, Reiter & Wichmann (222) found that 40.5% of women in their study actively sought out information about the influenza vaccine given during pregnancy.

Women that sought advice from their healthcare professional were significantly more likely to vaccinate than those who sort information elsewhere. Thirty-five percent reported a need for further information, primarily for vaccine side-effects whether for themselves or their unborn child (222). A similar result was reported in a survey related to the 2009/10 pandemic influenza vaccination (48) whereby the targeted at risk group, pregnant women, were found to use their healthcare professional as a source of information about the disease at a rate higher than that the general public.

4.2.3 Theoretical framework

Within the discipline of information science, Krikelas suggests that information needs occur when there is a perceived gap between currently held information and the level of

information that an individual feels they need in order to confidently make an informed decision (207).

A healthcare professional will often offer patients additional information to help inform them during an upcoming healthcare decision. Satisfaction with such information forms a key role within Wilson's model of information behaviour (36). If the given information does not significantly fill a person's unique information needs, information-seeking behaviour may occur. A successful information-seeking process is defined as leading to information being gathered and evaluated for use. Satisfaction or non-satisfaction with this new information gathered then serves to update the level of information need and amount of subsequent information-seeking behaviour (36).

Unmet information needs related to vaccination can often be stressful for a decision maker (50,214). Therefore, the process of information-seeking is often mentioned in terms of a coping strategy whereby individuals who hold an "*engaged coping strategy*" will aim to reduce psychological stress caused by uncertainty through an active process of seeking information (32).

Our view of vaccine information-seeking behaviour is that of an active process performed by an individual. As such, we take the behaviour to be a reasoned action that a person consciously performs as a means of satisfying unmet information needs. In this way we draw upon the model of risk information-seeking by Griffin, Dunwoody and Neuwirth (223) in which factors such as risk perception, beliefs, about information-seeking, and self-efficacy related to information gathering are important predictors of information sufficiency (satisfaction) and subsequent information-seeking behaviour.

This study aims to investigate to what degree the factors mentioned first, predicts levels of satisfaction with official information about the pertussis vaccination and second, predict

vaccine information-seeking behaviour during pregnancy. In addition, tools to measure the concept more effectively were developed for future research use (further details related to this can be found in Appendix D).

Hypothesis 1: We hypothesise that trust in healthcare professionals, trust in the healthcare system, psychosocial determinates of vaccine information-seeking behaviour, risk perception of vaccination during pregnancy, and an engaged coping strategy will significantly predict satisfaction with information.

Hypothesis 2: We hypothesise that trust in healthcare professionals, trust in the healthcare system, risk perception of vaccination during pregnancy, psychosocial determinates of vaccine information-seeking behaviour, engaged coping strategy, and satisfaction with information will significantly predict the occurrence of vaccine information-seeking behaviour.

4.3 Methods

4.3.1 Participants and Design

Women were recruited to participate in an online survey study conducted with the use of the survey client platform Qualtrics. To be eligible to participate in the study women had to meet three inclusion criteria, these were (i) to have given birth within the last six months of starting the survey, (ii) to have spent the majority of their pregnancy within England or Wales and (iii) class themselves as fluent in English.

We conducted an a-priori power calculation based on the maximum number of independent variables we intended to use in any of our analyses (11 variables), an alpha level of $\alpha = 0.05$ and an effect size of $d = 0.2$. This effect size was chosen as the smallest effect that was deemed as scientifically meaningful. A power calculation using the program G*Power (254) indicated that a sample of 136 would be sufficient to reach a power level of 0.95.

To recruit the participants, we contacted public baby and toddler groups (typically groups that organise events for 0-4 year olds) across England and Wales and asked the coordinators to forward an invitation email to group members for participation. Coordinators of 3,248 groups were contacted, 312 of which forwarded the invitation either in the form of a printed flyer or electronically through social media or e-mail. Further snowball sampling occurred through a request to pass on the participation link to interested parties once the survey had been completed. A total of 719 participants followed the link provided to start the survey between October 2016 and April 2017, when the survey was closed as we reached our goal of over 350 fully completed responses. Of the 719 participants, 149 were excluded automatically due to not fulfilling one of the three inclusion criteria, 211 dropped out before full completion of the survey and 45 were excluded because they reported on the survey that they were unaware of the pertussis vaccination program during pregnancy; thus, 314 women were included in the subsequent analyses (this process of exclusion and dropout is illustrated in Figure 8).

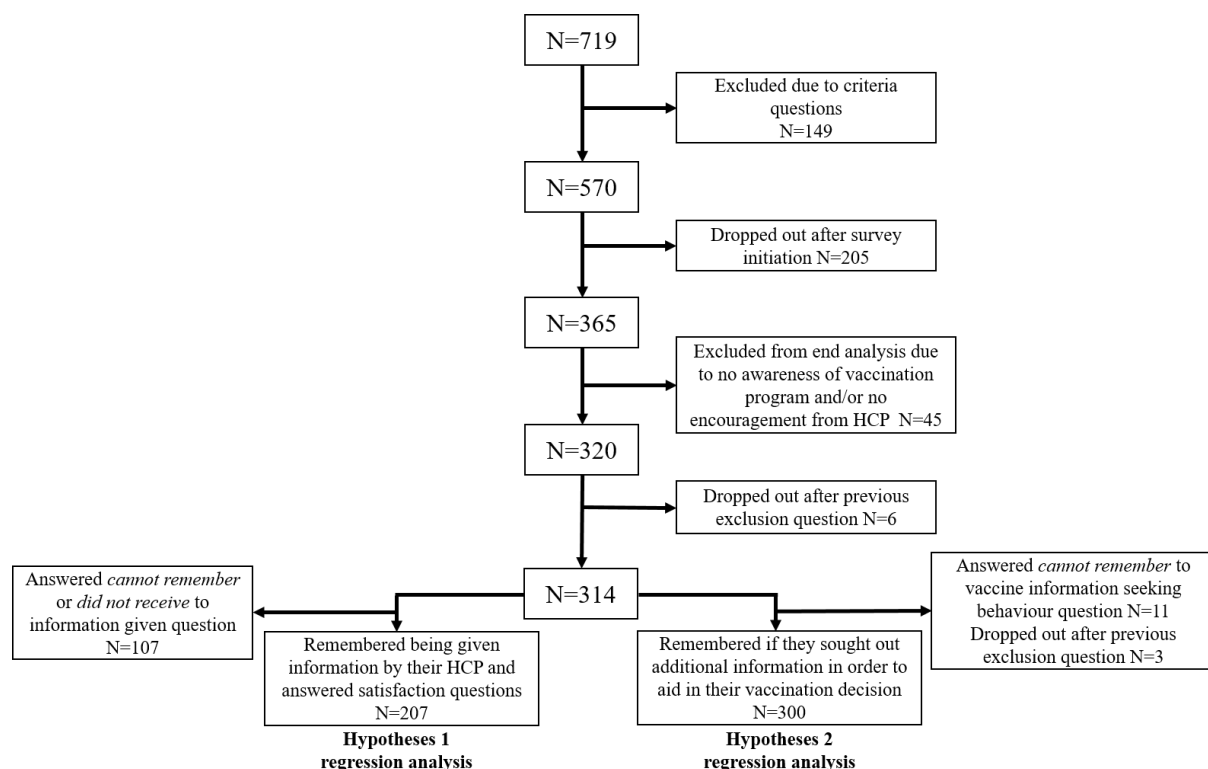


Figure 7: Flowchart of participant exclusion and drop out

The sample of participants who fully completed the survey (N=314) had an age range of between 18 and 46 with the mean age of 32.2 years ($SD = 4.6$ years). For 42.8% the recent birth was their first pregnancy. The majority of participants were white British (87%) and the sample was geographically diverse across England and Wales with no one outward geographical code (first three or four digits of postcode) representing more than 2.7% of the sample.

The study involved a cross-sectional, self-reported questionnaire (see Appendix E for full survey) designed to be taken online. If the 45 participants that were excluded from the later analysis for not being aware of the pertussis during pregnancy vaccination programme are taken into account, and assumed to have not vaccinated, the uptake rate across the sample was 81.4%.

4.3.2 Procedure and Measures

After providing informed consent, participants answered a range of questions related to socio-demographic factors such as age, location, ethnicity, and number of previous pregnancies that reached the third trimester. The questionnaire that followed contained a range of psychometric measures. The following subheadings outline the included scales and measures. These were presented to participants in the same fixed order as presented here. On completion, all participants received a full debriefing of the study and were provided with an open text box for any further comments they would like to make.

4.3.2.1 *Trust in healthcare professionals and trust in the healthcare system*

To measure trust in an individual's primary healthcare professional we adopted The Wake Forest Scale of Physician Trust (76) with the sole substitution of *healthcare professional* for *physician*. The scale consists of ten statements related to trust in primary healthcare professionals (e.g., "*Your healthcare professional did whatever it took to get you all the care you needed during your pregnancy*") that are assessed on a five-point Likert scale ranging

from strongly disagree (1) to strongly agree (5). The scale has good internal consistency (Cronbach's $\alpha = .94$) and the final score was expressed as an average of all items with the higher number indicating more trust.

To measure trust in the wider healthcare system we used The Healthcare System Distrust Scale (138). The scale consists of nine statements related to trust in the healthcare system (e.g., "*The healthcare system does its best to make patients' health better*") that are assessed on a five-point Likert scale ranging from strongly disagree (1) to strongly agree (5). This scale also has good internal consistency (Cronbach's $\alpha = .84$). Items were reverse coded to indicate trust in the healthcare system (rather than distrust) and the final score for the variable was expressed as the sum of the scores of all nine items.

4.3.2.2 Coping strategies

The Short-Form Coping Strategies Inventory (224) involves a participant first recalling and describing a recent event (within the last month) that they found particularly stressful. The participant then responds to 32 items related to how they coped with the previously described stressor (e.g., "*I tackled the problem head on*") that are assessed on a five-point Likert scale ranging from strongly disagree (1) to strongly agree (5).

The scale consists of first-order and second-order subscales. For the purpose of this study the first order scale of *disengaged* and two second order subscales of *emotion-focused engaged* and *problem-focused engaged* were used for testing the aforementioned hypotheses. The subscales had good internal consistency (*problem-focused engaged* Cronbach's $\alpha = .808$, *emotion-focused engaged* Cronbach's $\alpha = .89$, and *disengaged* Cronbach's $\alpha = .83$) and the final score for each was expressed as the sum of the scores of all items within each subscale, with the higher number indicating a greater propensity to adopt that coping strategy.

4.3.2.3 Psychosocial determinants of vaccine information-seeking behaviour

The Psychosocial Determinants of Vaccine Information-Seeking Behaviour Scale is an adapted version of a similar scale originally outlined in Harmsen et al. (188). Its original Dutch context (information-seeking related to the Dutch National Immunisation Program) was adapted to that of general vaccination. The scale measures beliefs about information-seeking, perceived social norms to information-seeking and perceived self-efficacy when seeking information. The scale draws on the model of risk information-seeking behaviour by Griffin, Dunwoody and Neuwirth (223) and on a theory of planned behaviour approach to behavioural intention (225). The scale has 16 statements (e.g., “*My friends think I should look for additional information when making a vaccination decision*”) that participants rated on a seven-point Likert scale ranging from Totally Disagree (1) to Totally Agree (7). A four-factor model is proposed whereby the final score is expressed as an average of all items within the factor with the higher number indicating higher likelihood of behavioural intention. A full account of the scales development using principal components analysis can be found in the supplemental materials (see Appendix D).

4.3.2.4 Risk perception of vaccination during pregnancy

The Risk Perception of Vaccination during Pregnancy Scale is a custom-made scale for use in this project tailored to measure risk perception. It has its bases in the severity and susceptibility elements of the Health Belief Model. This theoretical underpinning of a scale has been used in previous studies such as Henninger and colleagues (226), and Wallace and colleagues (227), this scale however captures attitude towards vaccination during pregnancy and the perceived susceptibility and severity for both pertussis as a disease and the pertussis vaccine offered during pregnancy. The scale consists of 10 statements (e.g., “*The whooping cough vaccine during pregnancy is likely to cause painful side effects*”) that are assessed on a five-point Likert scale ranging from strongly disagree (1) to strongly agree (5). The scale had questionable internal consistency (Cronbach $\alpha = .61$). The final score was expressed as a

subtraction of the vaccine related items from the disease related items with a lower value indicating a more negative perception of risk related to the pertussis vaccinations given during pregnancy.

4.3.2.5 Satisfaction with information

This short scale, constructed for use in this study, asks participants to rate information based on perceived amount, clarity, and accuracy. The scale consists of three statements related to satisfaction (e.g., “*How satisfied were you with the clarity of the information given to you by your healthcare professional(s)?*”) that are assessed on a seven-point Likert scale between highly dissatisfied (1) to highly satisfied (7). The scale has good internal consistency (Cronbach’s $\alpha = .91$) and the final score was expressed as an average of all items with higher number indicating higher satisfaction with information.

4.3.2.6 Vaccine information-seeking behaviour

For the purposes of this study the variable of *vaccine information-seeking behaviour* was quantified as a binary yes/no for the question (“*Did you seek out or research additional information about the whooping cough vaccine or whooping cough as a disease to help you make your decision? This could be from searching on the internet, talking to a friend or family member, reading pregnancy books, talking to other health professionals or anything else that would have aided you in your decision*”). An option of cannot remember was included whereby individuals who selected this option were excluded from analysis.

4.3.3 Statistical analyses

Statistical analyses were carried out using SPSS v.24 for Windows. In the following results section, the sample is described using a range of descriptive statistics then each of the hypotheses are explored. Two regressions analyses were conducted to assess the predictive ability of the listed variables on *satisfaction with information*, and *vaccine information-seeking behaviour*. Before running each model, zero-order correlation checks were conducted in order to check for any obvious multicollinearity issues.

In order to reduce the chance of false positive findings in each of the regression models a Bonferroni adjustment was made. This involved the use of a more stringent alpha value which was derived by taking an alpha level of .05 and dividing the value by the number of independent variables in each test. As such, the alpha level for model one was set at .005 and the alpha level for model two was set at .0045.

To test hypothesis one, a multiple linear regression model was conducted, with the predictor variables of *coping strategy*, *trust in healthcare professional*, *trust in healthcare system*, *risk perception of vaccination during pregnancy*, and *psychosocial determinates of Vaccine information-seeking behaviour* being used to predict the variable *satisfaction with information*.

To test hypothesis two, a logistic regression model was conducted with the predictor variables of *coping strategy*, *trust in healthcare professional*, *trust in healthcare system*, *risk perception of vaccination during pregnancy*, *psychosocial determinates of vaccine information-seeking behaviour* and *satisfaction with information* being used to predict the variable *vaccine information-seeking behaviour*.

After the initial regression analysis when testing this second hypothesis, a post-hoc backwards stepwise logistic regression was conducted to further explore the predictors in the model. The alpha level was again adjusted, according to the Bonferroni adjustment, to .007 based on the number of remaining variables.

To determine the robustness of each of the findings sensitivity analyses were conducted.

This involved the conducting of identical analysis with the inclusion of further demographic variables as possible conflicting variables. These variables included to check for their possible confounding effects were the participants age, ethnicity and number of previous pregnancies (parity).

4.4 Results

4.4.1 Descriptive statistics

For the participants that were aware of the antenatal pertussis vaccination program, 94.9% of participants had been vaccinated against pertussis during their recent pregnancy, with 95.8% receiving the vaccine between week 17 and week 36 of their pregnancy (see Table 6). Fifty-two percent of the sample reported becoming aware of the vaccination during their most recent pregnancy with midwives being found to be both the means that an individual first heard about the vaccination program (77.4%) and the healthcare professional to give the mother the most encouragement to vaccinate (91.4%).

Table 6: *General pertussis vaccine single item questions summary*

Questions	Number	%
Did you receive the whooping cough vaccine during your last pregnancy?		
Yes	297	94.9
No	16	5.1
When did you become aware that the whooping cough vaccine is recommended for pregnant women?		
Before last pregnancy	144	45.9
During last pregnancy	165	52.5
Cannot remember	5	1.6
Approximately how many weeks pregnant were you when you had the whooping cough vaccination?		
<17 Weeks	7	2.4

Between 17 and 26 Weeks	109	37
Between 27 and 36 Weeks	173	58.8
>36 Weeks	5	1.7
How did you first become aware about the whooping cough vaccination given during pregnancy?		
Leaflet with an appointment letter	16	5.1
During a meeting with a midwife	243	77.4
During a meeting with an obstetrician	4	1.3
During a meeting with a GP	6	1.9
During a meeting with a health visitor	2	0.6
During a meeting with a nurse	1	0.3
Public Health Campaign	3	1.0
Media (TV, Newspaper)	2	0.6
Friend or family member	16	5.1
Do not remember	4	1.3
Other	17	5.4
Out of the healthcare professionals you saw during your pregnancy which (if any) gave you the most encouragement to receive the whooping cough vaccine?		
Midwives	287	91.4
Obstetrician	2	0.6
GP	10	3.2
Health Visitor	2	0.6

Nurse	8	2.5
Pharmacist	1	0.3
Consultant	4	1.3

For the individuals who reported seeking additional information to aid in their decision making process 88.1% indicated using online sources (with 41.7% citing only web 1.0 and 0.07% citing only the use of web 2.0 and 39.4% using both), 42.5% talked to friends or family members and 7.1% sought out an additional healthcare professional (see Table 7). For those women who did search for additional information, time spent searching for information varied from 8 minutes to 11 hours (mean= 2 hours 31 minutes).

Table 7: *Vaccine information seeking behaviour single item questions*

<i>Questions</i>	<i>Number</i>	<i>%</i>
Did you seek out or research additional information about the whooping cough vaccine or whooping cough as a disease to help you make your decision?		
No	177	56.9
Yes	123	39.5
Cannot remember	11	3.5
If yes, where did you go for this additional information?		
The internet (articles and news) e.g. NHS Choice, Net doctor	103	81.1
The internet (Forums and discussion with other women) e.g. Mumsnet, Netmums, Facebook, Twitter	59	46.5
Friends and family members	54	42.5

Parenting and pregnancy books and magazines	17	13.4
Another NHS healthcare professional	7	7.1
A complementary/alternative healthcare professional	5	3.9
A private healthcare professional	3	2.4
e-books	1	0.8
Religious leaders	0	0
Other	6	4.7

4.4.2 Predicting Information Satisfaction (Testing hypothesis one)

Through a zero-order correlations analysis (Table 8) we observed several weak to moderate correlations between *trust in healthcare professional*, *trust in healthcare system*, *problem-focused engaged coping strategy*, *perceived behaviour control of vaccine information-seeking behaviour*, *risk perception of vaccination during pregnancy*, and *satisfaction with information*. While significant correlations were found between variables included in the regression model the Variance Inflation Factor (IVF) statistics, a statistic that measures how much the behaviour of an independent variable is influenced by its interaction with the other independent variables, demonstrated low multicollinearity, with none of the values exceeding an IVF of 2.0 (see Table 9).

Table 8: Zero order correlations among variables in model 1 (N=207)

*p<.0045 (as corrected for multiple hypothesis testing)

Variable	1	2	3	4	5	6	7	8	9	10	11
1. Trust in healthcare system	-										
2. Trust in healthcare professional	.507*	-									
3. Disengaged coping style	.048	.019	-								
4. Problem engaged coping style	.184	.043	-.191	-							
5. Emotion engaged coping style	.080	.100	.071	.318*	-						
6. Psychosocial determinants of VISB factor 1: Attitudes and beliefs	-.067	-.063	.075	.105	.024	-					
7. Psychosocial determinants of VISB factor 2: Descriptive norms	.093	.014	.145	.135	.047	.514*	-				
8. Psychosocial determinants of VISB factor 3: Injunctive norms	.039	.071	-.028	.024	-.048	.390*	.327*	-			
9. Psychosocial determinants of VISB factor 4: Perceived behavioural control	.235*	.118	.076	.165*	.122	.348*	.177	.081	-		
10. Risk Perception of vaccination during pregnancy	.286*	.192	-.053	-.060	.026	-.063	.010	.020	.161	-	
11. Satisfaction with information	.370*	.401*	.080	.208*	.081	.018	.107	.084	.279*	.252*	-

Vaccine information-seeking behaviour (VISB)

In a regression model the variables significantly predicted *satisfaction with information* $F(10, 185) = 9.436, p < .001$. This successfully accounted for 33.8% of the variance. We found three significant predictors of *satisfaction with information* (see Table 9): a *problem-focused engaged coping strategy*, *trust in healthcare professional*, and *perceived behavioural control of vaccine information-seeking behaviour*. These variables remained significant after a Bonferroni correction for multiple comparisons. A higher rating on all three variables predicted a higher likelihood that the respondent would report being satisfied with the information presented to them by their healthcare professional.

Table 9: *Psychosocial predictors of the satisfaction with vaccine information (multiple regression analysis)*

Variable	<i>B</i>	95% <i>CI</i>		<i>t</i>	<i>p</i>	<i>VIF</i>
		<i>Lower</i>	<i>Upper</i>			
Constant	0.601	-.547	3.173			
Trust in healthcare system	0.013	-.047	.020	0.779	.437	1.581
Trust in healthcare professional	0.467	.271	.663	4.698	< .001	1.383
Disengaged coping style	0.011	-.002	.025	1.647	.101	1.118
Problem engaged coping style	0.042	.016	.068	3.163	.002	1.283
Emotion engaged coping style	-0.010	-.031	.012	-0.884	.378	1.161
Psychosocial determinants of VISB factor 1: Attitudes and beliefs	-0.091	-.24	.058	-1.202	.231	1.700
Psychosocial determinants of VISB factor 2: Descriptive norms	0.034	-.076	.143	0.607	.544	1.450
Psychosocial determinants of VISB factor 3: Injunctive norms	0.056	-.063	.174	0.929	.354	1.250
Psychosocial determinants of VISB factor 4: Perceived behavioural control	0.240	.078	.401	2.923	.004	1.289

Risk Perception of vaccination during pregnancy	0.234	.068	.401	2.778	.006	1.138
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Alpha was $p < .005$ as adjusted for multiple comparisons

Unstandardized Beta coefficient B

Variance inflation factor (VIF)

Vaccine information-seeking behaviour (VISB)

The beta values in this analysis indicate the amount of change in *satisfaction with vaccine information* due to a change of 1 unit for each of the independent variables included in the model. For example for every one unit change in *trust in a health care professional* (as scored between 1 and 5), *satisfaction with information* (as scored between 1 and 7) changes by almost half a unit.

To check the robustness of the findings from this model a sensitivity analysis was conducted using the available demographic variables that are frequently mentioned as important in previous literature. These variables included age, ethnicity and number of previous pregnancies (parity).

Table 10: *Sensitivity analysis for predictors of the satisfaction with vaccine information*

Variable	B	95% CI		t	p
		<i>Lower</i>	<i>Upper</i>		
Constant	1.205	-.968	3.378		
Trust in healthcare system	.012	-.045	.022	-.669	.505
Trust in healthcare professional	.465	.266	.663	4.618	<.001
Disengaged coping style	.011	-.003	.025	1.614	.108
Problem engaged coping style	.045	.018	.071	3.276	.001
Emotion engaged coping style	-.011	-.033	.011	-.993	.322
Psychosocial determinants of VISB	-.092	-.243	.058	-1.209	.228
factor 1: Attitudes and beliefs					

Psychosocial determinants of VISB	.04	-.074	.153	.693	.489
factor 2: Descriptive norms					
Psychosocial determinants of VISB	.049	-.073	.17	.792	.429
factor 3: Injunctive norms					
Psychosocial determinants of VISB	.257	.09	.424	3.041	.003
factor 4: Perceived behavioural control					
Risk Perception of vaccination during pregnancy	.243	.069	.417	2.756	.006
Age	-.007	-.04	0.26	-.433	.665
Parity	.039	-.168	.245	.369	.713
Ethnicity	.077	-.417	.57	.306	.760

Unstandardized Beta coefficient *B*

Vaccine information-seeking behaviour (VISB)

Shading indicates the adjusting for the variables: years of age, parity (number of previous pregnancies) and ethnicity (binary variable white/other ethnicity selected).

When the additional variables are taken into account (Table 10) the findings remain the same indicating that these variables play little in the way of a role in predicting *satisfaction with information*.

4.4.2 Predicting Information-Seeking Behaviour (Testing hypothesis 2)

Through a zero-order correlations analysis (Table 11), we observed several weak to moderate correlations between *trust in healthcare professional*, all four subscales of the Psychosocial Determinants of Vaccine Information-Seeking Behaviour Scale, and *satisfaction with information*. While significant correlations were found between variables included in the regression model the VIF statistics demonstrated low multicollinearity, whereby none of the values exceeded a VIF of 2.0 (see table 12).

Table 11: *Zero order correlations among variables in model 2 (N=300)*

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Trust in healthcare system	-											
2. Trust in healthcare professional	.551*	-										
3. Disengaged coping style	.042	-.034	-									
4. Problem engaged coping style	.210	.071	-.218*	-								
5. Emotion engaged coping style	.051	.116	-.778	.298*	-							
6. Psychosocial determinants of VISB factor 1: Attitudes and beliefs	-.115	-.119	.107	.093	-.006	-						
7. Psychosocial determinants of VISB factor 2: Descriptive norms	.002	-.029	.109	.078	.063	.584*	-					
8. Psychosocial determinants of VISB factor 3: Injunctive norms	-.069	-.027	.026	.034	-.075	.436*	.381*	-				
9. Psychosocial determinants of VISB factor 4: Perceived behavioural control	.207*	.121	.054	.160	.069	.311*	.185	.102	-			

10. Risk Perception of vaccination during pregnancy	.300*	.230*	-.105	-.080	.050	-.141*	.041	-.065	.158	-		
11. Satisfaction with information	.373*	.397*	.064	.221*	.109	.017	.104	.090	.270*	.256*	-	
12. Vaccine information seeking behaviour [†]	-.080	-.148	.083	.028	-.065	.402*	.279*	.178	.129	-.053	-.145	-

*p<.0041 (as corrected for multiple hypothesis testing), [†] Point-biserial correlations (r_{pb})

Vaccine information-seeking behaviour (VISB)

This model was found to be significant, $\chi^2(11) = 47.690$, $p < .001$ and predicted 30.2% of the variance in *vaccine information-seeking behaviour*. Initially the variables of *satisfaction with information* and the attitude and beliefs component of the *psychosocial determinates to vaccine information-seeking behaviour* scale were found to be significant within the model, however after the Bonferroni correction for multiple comparisons this significance was lost. The Hosmer and Lemeshow test demonstrates the data violates parametric assumptions for the model, $\chi^2(8) = 16.564$, $p = .035$.

Table 12: *Psychosocial predictors of vaccine information seeking behaviour (logistic regression analysis)*

Variable	B	Odds ratio	95% CI		p	VIF
			Lower	Upper		
Constant	-5.050					
Trust in healthcare system	.033	1.033	0.959	1.113	.421	1.631
Trust in healthcare professional	-.161	.852	.522	1.389	.520	1.595
Disengaged coping style	.025	1.025	.993	1.058	.120	1.137
Problem engaged coping style	.051	1.052	.988	1.119	.111	1.385
Emotion engaged coping style	-.046	.955	.955	.908	.070	1.172
Psychosocial determinants of VISB factor	.556	1.743	1.161	2.617	.007	1.746
1: Attitudes and beliefs						
Psychosocial determinants of VISB factor	.244	1.276	.976	1.668	.075	1.483
2: Descriptive norms						
Psychosocial determinants of VISB factor	.074	1.076	.825	1.404	.587	1.252
3: Injunctive norms						
Psychosocial determinants of VISB factor	.240	1.272	.834	1.94	.264	1.58
4: Perceived behavioural control						
Risk Perception of vaccination during pregnancy	-.058	.944	.637	1.4	.774	1.215
Satisfaction with information given	-.493	.611	.432	.863	.005	1.519

Alpha was $p < .0045$ as adjusted for multiple comparisons

Unstandardized Beta coefficient B

Variance inflation factor (VIF)

Vaccine information-seeking behaviour (VISB)

We conducted a post-hoc backwards stepwise logistic regression to further explore the predictors in the model. From this, it was evident that the removal of the risk perception variable had no effect on the variance explained by the model. Furthermore, removing the variables *injunctive norms towards vaccine information-seeking behaviour*, *trust in healthcare professionals* and *trust in the healthcare system* together reduce the variance explained by only 0.8%. Therefore, the following model (see Table 13), with seven variables, would appear to be the most economical when predicting vaccine information-seeking behaviour.

Table 13: *Psychosocial predictors of vaccine information seeking behaviour (stepwise logistic regression analysis)*

Variable	B	Odds ratio	95% CI		p	VIF
			Lower	Upper		
Constant	-4.657					
Disengaged coping style	.025	1.026	.995	1.058	.105	1.102
Problem engaged coping style	.057	1.058	.998	1.122	.060	1.264
Emotion engaged coping style	-.048	.953	.907	1.001	.057	1.144
Psychosocial determinants of VISB factor 1: Attitudes and beliefs	.550	1.732	1.181	2.541	.005	1.502
Psychosocial determinants of VISB factor 2: Descriptive norms	.263	1.301	1.002	1.688	.048	1.398
Psychosocial determinants of VISB factor 4: Perceived behavioural control	.263	1.301	.865	1.956	.206	1.286
Satisfaction with information given	-.500	.607	.443	.831	.002	1.181

Alpha was $p < .007$ as adjusted for multiple comparisons

Variance inflation factor (VIF)

Unstandardized Beta coefficient B

Vaccine information-seeking behaviour (VISB)

The odds ratio for each variable indicates how much more (or less if the OR is below 1) likely an individual is to seek out information about vaccination for each unit increase of such variable. For example for each 1 unit decrease in *satisfaction with information* the chances of seeking out information about vaccination increases by .607, which to put another way suggests that the behaviour is 39.3% less likely.

This model was found to be significant, $\chi^2(7) = 46.582, p < .001$ and predicted 29.6% of the variance in *vaccine information-seeking behaviour*. The variables of *satisfaction with information* and the attitude and beliefs component of the *psychosocial determinates to vaccine information-seeking behaviour* scale were now found to be significant within the model. The Hosmer and Lemeshow test demonstrates the data did not violate parametric assumptions for the model, $\chi^2(8) = 8.994, p = .343$.

To check the robustness of the findings from this model a sensitivity analysis (Table 14) was conducted using the available demographic variables that are frequently mentioned as important in previous literature. These variables included age, ethnicity and number of previous pregnancies (parity). As with the previous model when the additional variables are taken into account the findings remain the same indicating that these variables do not play a role in vaccine information seeking behaviour.

Table 14: *Sensitivity analysis for the predictors of vaccine information seeking behaviour*

Variable	B	Odds ratio	95% CI		p
			Lower	Upper	
Constant	-4.238				
Disengaged coping style	.025	1.026	.994	1.058	.115
Problem engaged coping style	.054	1.056	.995	1.121	.074
Emotion engaged coping style	-.05	.951	.904	1.001	.053
Psychosocial determinants of VISB factor 1: Attitudes and beliefs	.545	1.725	1.173	2.535	.006

Psychosocial determinants of VISB factor 2:	.263	1.301	.998	1.697	.052
Descriptive norms					
Psychosocial determinants of VISB factor 4:	.271	1.311	.866	1.985	.2
Perceived behavioural control					
Satisfaction with information given	-.486	.615	.449	.843	.002
Age	-.008	.992	.922	1.068	.839
Parity	-.006	.994	.635	1.556	.979
Ethnicity	-.152	.859	.297	2.486	.779

Unstandardized Beta coefficient *B*

Vaccine information-seeking behaviour (VISB)

Shading indicates the adjusting for the variables: years of age, parity (number of previous pregnancies) and ethnicity (binary variable white/other ethnicity selected).

4.4.3 Further Notable Findings and Exploratory Analyses

Further exploratory analysis of the results given by the Psychosocial Determinate of Vaccine Information-Seeking Behaviour Scale demonstrated a significant difference across the subscales with the social (injunctive) norms to seeking information about vaccination constantly rated as lower than the other factors $F(3,1086) = 377.5$ $p < .001$.

4.5 Discussion

Our findings indicate that seeking out further information in relation to the vaccines offered during pregnancy is a widely performed behaviour. We found that those women who trusted their healthcare professionals more, those who adopted a problem-focused engaged strategy when coping with stressful events and those who perceived higher behavioural control related to their own vaccine information-seeking behaviour, reported more satisfaction with the information received from their healthcare professional. This confirms our first hypothesis. Higher ratings in the three variables were found to relate to higher ratings of *satisfaction with information*.

When investigating hypothesis 2 the data used in our logistic regression model did not meet parametric assumption and to predict vaccine information-seeking behaviour and no single

individual measure within the module reached significance. In exploring the data further, however, it is suggested that satisfaction with official information related to the pertussis vaccine related to individuals spending less time seeking out additional information.

These findings, particularly those related to hypothesis 1, indicate that when official information is given to aid in the decision-making process it is often perceived in relation to a range of additional personality and social factors and not solely evaluated on its own intrinsic merit. The fact that *trust in healthcare professional* was found to be significant in the model, whereas *trust in the healthcare system* was not, gives evidence to Yaqub and colleagues (210) notion that social context predominantly shapes how information is interpreted and used. The importance of *perceived behavioural control of vaccine information-seeking behaviour* and *problem-focused engaged coping strategy* also adds to our understanding. Both of the constructs place factual information at the centre: (1) a problem-focused coping strategy is primarily related to cognitive and behavioural strategies to proactively change a stressful situation (224) and (2) behaviour control is the belief that a person is able to seek out and accurately assess information when needed (225). Therefore, individuals who value factual information (over, for example, emotional or social information) are likely to be more satisfied with official written information being supplied by their healthcare professional.

With midwives being predominantly the means that an individual first heard about the vaccination program (77.4%) and the healthcare professional to give the mother the most encouragement to vaccinate (91.4%) these findings highlight just how vital this role is for this particular vaccination program. In the past, midwives have stated their own self-efficacy issues in regards to communicating information about vaccination (61) as such this study gives further evidence to the necessity for additional midwife vaccine training and guidance.

It is noteworthy that the three coping strategy subscales did not play more of a sizable role in predicting vaccine information-seeking behaviour. From the theoretical framework outlined in the introduction we predicted that an engaged coping *strategy* would facilitate vaccine information-seeking behaviour whereas a disengaged coping *strategy* would inhibit it. Additional exploratory analysis of the Psychosocial Determinants of Vaccine Information-Seeking Behaviour Scale may indicate why this was the case. Although women in our study reported a desire to undertake searching (*Factor 1*) and feel that they had the necessary skills to do so (*Factor 4*) there were hints towards a possible social norm against the behaviour (*Factor 3*). Frequently, the items that asked whether the respondent thought that their healthcare professional or friends and family felt that they should seek additional information about vaccinations were rated as *disagree* or *strongly disagree*. Due to the Coping Strategy Scale being related to a general stress-causing event rather than medically specific, nuance such as the existence of a specific social norm such as those related to information-seeking may have been lost.

From the evidence we present here it is possible to say that for official sources of information to be seen in a positive light a relationship between the mother and her healthcare professional must be based on a solid foundation of trust. Furthermore, different individuals will place different levels of importance on the information given during the vaccine decision making process with those that value, and feel particularly skilled with, factual information reacting more positively towards factual information-based communications. These findings also perhaps bring in to question the level of real world applicability of purely information based interventions (228). Without suitable attention also being paid to the social and personal context in which this information is presented it is possible that the contents of the communicated information may go largely ignored.

4.6 Limitations

The theoretical framework allowed us to study many of the relevant factors in vaccine information-seeking behaviour, however it is possible that some concepts relevant to information search behaviour (e.g., *need for cognition*) were neglected by the model. Furthermore, caution also must be applied when interpreting these results given the self-selecting nature of our sample. The sample was predominantly vaccinated against pertussis during their pregnancy (81% of sample, 95% of those that had heard about the programme, compared to a 68% average across England (215)). It is notable, however, that even in this sample with above average levels of uptake, information-seeking still occurred within a sizable minority. This level of information-seeking occurred with many participants rating the social norms of seeking information particularly negatively possibly indicating vaccinating participants seek information but think that they should not be doing so. This high vaccinating sample, however, does not allow for many conclusions to be drawn as to how non-vaccinators view information seeking behaviour. That said, the fact that the invitation to the study did not include the topic of vaccination works to the benefit of the study, and with participation occurred entirely online, it may indicate that refusers of the vaccine are predominantly not found in the local community groups through which participants were recruited.

Furthermore, due to the retrospective nature of the survey it is not possible to rule out recall bias as a potential confounder within the survey. The act of either receiving or rejecting the vaccine may have led to individuals engaging in post hoc rationalising of the information-seeking acts that lead to such a decision. As such, investigating these concepts further would benefit from additional longitudinal research, potentially utilising a more intensive form data collection such as instructing a participant to keep an information diary.

4.7 Conclusion

This research indicates the complicated dynamic that exists between factual information and the context in which it is presented. In the case of vaccination during pregnancy, it is evident that trust held by a mother for her healthcare professional is of utmost importance if the mother is to feel satisfied with the information about vaccination that is presented to her.

RESEARCH PAPER COVER SHEET

PLEASE NOTE THAT A COVER SHEET MUST BE COMPLETED FOR EACH RESEARCH PAPER INCLUDED IN A THESIS.

SECTION A – Student Details

Student	Mr Richard M Clarke
Principal Supervisor	Dr Pauline Paterson
Thesis Title	Vaccine information-seeking behaviour: its predictors and influence on vaccination during pregnancy

If the Research Paper has previously been published please complete Section B, if not please move to Section C

SECTION B – Paper already published

Where was the work published?			
When was the work published?			
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Choose an item.	Was the work subject to academic peer review?	Yes

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SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	Human Vaccines & Immunotherapeutics
Please list the paper's authors in the intended authorship order:	Mr Richard Clarke, Dr Pauline Paterson & Dr Miroslav Sirota
Stage of publication	In press

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)

I designed the studies, collected the data, conducted the analyses and wrote the manuscript. Dr Pauline Paterson and Dr Miroslav Sirota supervised and gave regular feedback during this process and confirmed the work before submission.

Student Signature: _____

Date: _____

Supervisor Signature: _____

Date: _____

5. Do previously held vaccine attitudes dictate the extent and influence of vaccine information seeking behaviour during pregnancy?

5.1 Abstract

Pregnancy represents a high information need state, where uncertainty around medical intervention is common. As such, the pertussis vaccination given during pregnancy presents a unique opportunity to study the interaction between vaccine attitudes and vaccine information seeking behaviour.

We surveyed a sample of pregnant women ($N = 182$) during early pregnancy and again during late pregnancy. The variables of vaccine confidence and risk perception of vaccination during pregnancy were measured across two questionnaires. Additional variables of decision conflict and intention to vaccinate were recorded during early pregnancy, while vaccine information-seeking behaviour and vaccine uptake were recorded during late pregnancy.

88.8% of participants reported seeking additional information about the pertussis vaccine during pregnancy. Women that had a lower confidence in vaccination ($p = .004$) and those that saw the risk of pertussis disease as high compared to the risk of side effects from the pertussis vaccination during pregnancy ($p = .004$), spent significantly more time seeking information about the pertussis vaccination.

Women's perception of risk related to vaccination during pregnancy significantly changed throughout the pregnancy ($t(182) = 4.685$ $p < .001$), with women perceiving the risk of pertussis disease higher as compared to the risk of side effects from the vaccine as the pregnancy progresses. The strength and influence of information found through seeking was predicted by intention to vaccinate ($p = .011$). As such, we suggest that intention to vaccinate during early pregnancy plays a role in whether the information found through seeking influences women towards or away from vaccination.

5.2 Introduction

When facing a vaccination decision, people often commit substantial time and effort to seeking out additional information in regards to the vaccine, the disease the vaccine protects against, and the systems related to the vaccination programme. Vaccine information-seeking behaviour is common in individuals regarding their own immunisation (48,106,161,186,199), and the immunisation of their children (159,166,168,173,188,229). This seeking behaviour frequently relates to the perception of previously acquired information as inadequate (46,168,198), confusing (181,230) or conflicting (196). Consequently, a person may seek information about vaccination to feel reassured about a decision, get a ‘second opinion’ or prepare for a consultation with a healthcare professional (74,196), sometimes with the intention of challenging a recommendation (231,232). The content of such information gathered through seeking often centres around safety concerns related to a specific vaccine (196), the signs and symptoms of a disease the vaccine is intended to prevent (198) or gaining information on aspects of trust and morality such as financial interests, misconduct and intentions of individuals within the healthcare system or pharmaceutical industry (231). As such, the information gained through vaccine information-seeking can be categorised as information pertaining to trust and personal risk management (233).

Such vaccine information-seeking behaviour is present in a sizable minority of both individuals that accept (186,229) but also those that decline (106,161,199) vaccination. The binary distinction of searching or not searching for additional vaccine information, therefore, appears to be a poor predictor of overall vaccine uptake. Extent of vaccine information-seeking behaviour however, may prove a reliable indicator of vaccine refusal, with extensive information seeking being associated with vaccine hesitant beliefs and behaviours, such as delay in acceptance or refusal of vaccines despite vaccine availability (173,229,234). A

reliable relationship also appears to exist between the channels¹ of information that are utilised during the information seeking process and the likelihood of vaccinating.

People seeking information from a healthcare professional, or the wider healthcare system, are substantially less likely to refuse vaccination (147,235). Concerns exist, however, in regards to those individuals that seek information predominantly through other means, such as the internet or friends and family members. Numerous studies have documented that the internet is rife with misinformation about vaccination (21,22,29,236) and that such misinformation can flow through intimate, online and offline, social networks (237,238). Furthermore, the work by Betsch and others (148,212,239) demonstrates that after consuming misinformation critical of vaccination, for as little as five to ten minutes in some cases (239), individuals perceive the risk related to vaccination significantly higher, and the risk related to not vaccinating as significantly lower, than those viewing control information.

With pregnancy often cited as a high information need state (51,219) and events such as the thalidomide tragedy (240) cementing the teratogenic risks of pharmaceutical products in the minds of many parents-to-be (241–244), vaccination during pregnancy lends itself well to the examination of vaccine information-seeking behaviour. Due to the sessional variability of the influenza during pregnancy vaccine, we selected the vaccination of pertussis (also known as whooping cough) during pregnancy as the vaccine decision of interest for this current study.

Women in the UK are currently recommended an immunisation for pertussis during each pregnancy (53). With waning immunity and increased levels of circulation of the disease in

¹ Throughout this study, we make a distinction between a “channel” of information and a “source” of information. We take Rogers and Shoemaker’s definitions whereby an information channel is, “the means by which the message gets from the source to the receiver” (Rogers & Shoemaker. 1971, pp.24, cited from Johnson & Case 2012, pp 32), while an information source is, “...an individual or an institution that originates a message” (Rogers & Shoemaker. 1971, pp.251, cited from Johnson & Case 2012, pp 33). With such definitions, a single source of information, such as the NHS, can communicate through multiple channels (for example, the NHS can communicate vaccine information through a healthcare professional and through their website). Our study predominantly focuses on channels of information as opposed to sources of information.

adolescent and adult population (245) a sizable outbreak of pertussis occurred in 2012 prompted the introduction of this additional pertussis vaccination campaign. Vaccinating during pregnancy grants mothers immunity from pertussis during their pregnancy and passes on immunity to their babies, protecting children during the crucial first few weeks of life until they are old enough to receive their own vaccinations for the disease (246–248). Latest uptake statistics of the recommended pertussis containing vaccine (Boostrix IPV) during pregnancy in the UK are approximately 71.9% (April- June 2018) (246) indicating the successful initial implementation of the program, however, there still exists considerable room for improvement.

With the present study, we investigated vaccine information-seeking behaviour over the course of the pregnancy vaccination decision-making process with three main aims. First, we wanted to determine the extent to which previously held vaccine hesitant attitudes during pregnancy, are associated with the extent and perceived influence of vaccine information-seeking behaviour. We hypothesised that lower levels of vaccine confidence, higher perception of risk associated with the vaccine, higher decision conflict and lower intention to vaccinate would predict higher total number of hours of vaccine information-seeking behaviour (Hypothesis 1) as well as the perceived strength, and direction of influence, of information found through seeking (Hypothesis 2). Second, we wanted to investigate the predictor variables of accepting the pertussis vaccine during pregnancy. We hypothesised that lower perception of risk associated with the vaccine, higher vaccine confidence, higher intention to vaccinate, higher strength of recommendation from a healthcare professional and the behaviour of information-seeking would positively predict vaccine uptake (Hypothesis 3). Third, we wanted to examine whether the strength of recommendation from a healthcare professional, the behaviour of vaccinating and the behaviour of seeking information during the decision-making process predict a change in attitude towards vaccination between early

and late pregnancy (Hypothesis 4). See Figure 8 for a series of conceptual map for the above study hypotheses

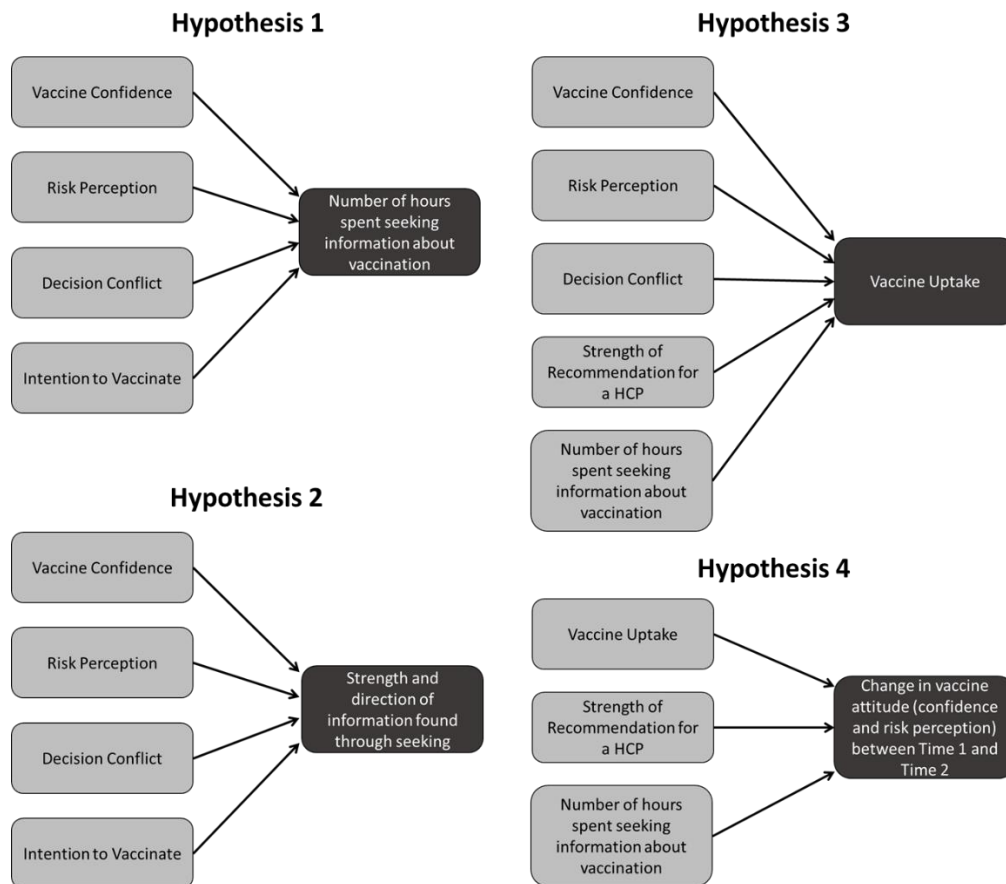


Figure 8: Conceptual maps for study hypotheses. The arrows indicate the predicted relationships between variables.

Finally, we also had some exploratory aims, specifically we asked two research questions.

The first being, how often do women use the various channels of vaccine information (friends and family members, healthcare professionals and the internet) and how influential do they perceived them? And the second being, do the various channels of information used by participants differ across vaccine uptake and non-uptake?

5.3 Methods

5.3.1 Design Overview

To examine the decision-making process, we designed a two-part cross-sectional questionnaire study: before and after a prompt to vaccinate. In the first part (Questionnaire T1), we gathered responses from women early in their pregnancy (>4 and <18 weeks of their pregnancy) -- before the decision to vaccinate for pertussis is usually prompted by a healthcare professional. In the second part (Questionnaire T2), we gathered information from the same women after they made their decision whether to take or not take the recommended vaccine (after the 36th week of their pregnancy).

5.3.2 Participants and Procedure

To be eligible to participate in our study, women were required to be (i) fluent in English, (ii) between 4 and 18 weeks of pregnancy, and (iii) currently living in England or Wales.

Recruitment of this sample first involved identifying a range of public groups and relevant professionals related to pregnancy (e.g. antenatal groups, yoga groups, doulas and hypnobirthing practitioners) through the use of the local pregnancy/antenatal listings on the website www.netmums.com. From the listings, 1,664 potentially suitable group leaders were identified across England and Wales.

During June and July 2017, a contact email was sent to each identified group leaders. This email contained an outline of our project and a request for the group leaders to pass on a participant invitation email, or share a similar social media message, to women in their network that they believe would be eligible to participate in our study. Non-responding group leaders received an additional follow up email sent two weeks after the initial contact email.

Of the group leaders contacted, 198 (11.9%) forwarded our invitation to pregnant women in their network, 179 (10.8%) responded that they were not interested or did not feel that their network would be interested in participating; 167 (10.0%) email addresses were confirmed as out of action, and 1120 (67.3%) did not respond to either of our two requests. Further

snowball sampling occurred through a request to pass on the participation link to potentially interested parties, at the end of the survey.

We conducted an a-priori power calculation based on the maximum number of independent variables we intended to use in any of our analyses (5 variables), an alpha level of $\alpha = 0.05$ and an effect size of $d = 0.2$. This effect size was chosen as the smallest effect that was deemed as scientifically meaningful. A power calculation using the program G*Power (254) indicated that a sample of 105 would be sufficient to reach a power level of 0.95. Due to each hypothesis requiring full completion of both studies we aimed to recruit approximately 300 participants with the assumption of a possible 50% attrition rate between Questionnaire T1 and Questionnaire T2.

From this we estimated that a total sample size of 150 participants fully completing both Questionnaire T1 and Questionnaire T2 would be an appropriate total number of to aim for. With the further assumption of a 50% attrition rate, between T1 and T2, we aimed to recruit around 300 participants to complete Questionnaire T1. This study received ethical approval from the London School of Hygiene and Tropical Medicine ethical committee on 12/05/2017 (LSHTM ethics code REF:13898)

A total of 357 participants followed the link provided to start Questionnaire T1 between June and November of 2017. Of these 273 participants fully completed Questionnaire T1. At the end of Questionnaire T1 participants were asked to provide a contact email address and with the explanation that this information was needed so as to recontact the participant later in their pregnancy for the second half of the study, and was not to be linked to their questionnaire data. A question indicating the current number of weeks pregnant in Questionnaire T1 was used to dictate when a follow up message with the link to Questionnaire T2 was to be sent to the participant (i.e. >36 weeks of pregnancy). The first

question on this second questionnaire asked participants to input their email address so that we could later link the responses across the two questionnaires.

When subsequently re-contacted, 193 of the 273 participants that fully completed the questionnaire at time 1 clicked on the link to start the questionnaire at time 2, with 187 participants fully completing Questionnaire T2 (31.5% attrition rate). To test each of the hypotheses full data was required from both Questionnaire T1 and Questionnaire T2.

To check of bias in attrition between the two questionnaires, a t-test was conducted for the dependent variable of vaccine confidence at T1 comparing those that completed Questionnaire T2 and those that only completed Questionnaire T1. There is no significant difference in attitudes towards vaccination at T1 between those that dropped out of the study between T1 and T2 and those that continued to give data for the second questionnaire, $t(270) = 0.371$ $p = .711$.

5.3.3 Participant demographics

After the removal of outliers (see the Results section for more detail), 182 participants were included in the final data analysis. The recorded socio-demographic characteristics of the participants are reported in table 15. Participants were predominantly White British (88.5%) and aged 22-42 years ($M = 31.97$, $SD = 3.84$ years). 21.4% of participants reported their current pregnancy as their first pregnancy, the week of pregnancy at Questionnaire T1 were equally spread across the required 4 to 18-week range, and 94.5% of participants were aware of the pertussis vaccination programme during pregnancy. When re-contacted for Questionnaire T2 after 36 weeks of pregnancy, 89.6% reported having received the pertussis vaccine during their pregnancy.

Table 15: *Characteristics of sample and descriptive statistics*

<i>Questions (N=182)</i>	<i>Number (%)</i>	
Age years		
20-24 yrs	5	(2.7)
25-29 yrs	48	(26.4)
30-34	80	(44.0)
35-39 yrs	46	(25.3)
40+ yrs	3	(1.6)
Ethnicity		
White - British	161	(88.5)
White - Other white background	11	(6.0)
Mixed/Multiple ethnic groups	8	(4.4)
Asian or Asian British	1	(0.5)
Other ethnicity not represented	1	(0.5)
Week of pregnancy during T1 questionnaire		
4-8 weeks	58	(31.9)
9-13 weeks	60	(33.0)
14-18 weeks	64	(35.1)
Number of pregnancies		
First pregnancy	39	(21.4)
1-2 previous pregnancies	134	(73.6)
3+ previous pregnancies	9	(4.9)
Number of participants aware of the pertussis vaccination during pregnancy at T1		
Yes	172	(94.5)
No	6	3.3
Not sure	4	(2.2)
Uptake of vaccine during pregnancy		
Yes	163	(89.6)
No	18	(9.9)
Cannot remember	1	(0.5)

5.3.4 Scales and Measures

The content of each questionnaire was as follows (a full description of each included scale of measurement is included thereafter):

Questionnaire T1 – Pre-decision: This questionnaire included a number of demographic and control questions, followed by two psychometric scales: *Risk Perception of Pertussis vs Pertussis Vaccination during Pregnancy Scale* and the *Vaccine Confidence Scale*. All participants were then presented with NHS information related to the pertussis vaccination campaign in pregnancy, asked to indicate their intention to vaccinate against pertussis during their pregnancy and complete *the decision conflict scale* in regards to their upcoming vaccination decision.

Questionnaire T2 – Post-decision: This questionnaire again included the *Risk Perception of Pertussis vs Pertussis Vaccination during Pregnancy Scale* and the *Vaccine Confidence Scale* used in the Questionnaire T1. Participants were then asked to report if they received the pertussis vaccine during their pregnancy, their vaccine information-seeking behaviour during the intervening period and the perceived influence of sought information.

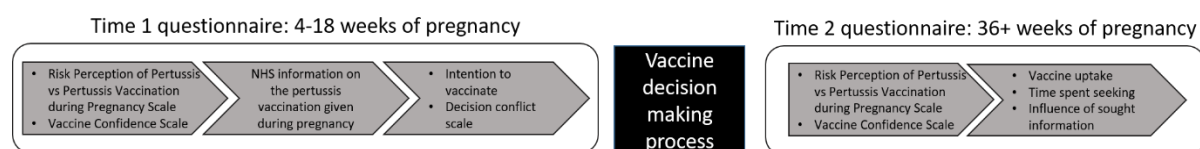


Figure 9: Schematic outline of experimental procedure

The following sections outline the psychometric scales and measures included in the study.

The full version of the two questionnaires, as seen by the participants at each time point, can be found in the provided supplemental materials (Appendix F).

5.3.4.1 The Risk Perception of Pertussis vs Pertussis Vaccination during Pregnancy Scale

The *Risk Perception of Pertussis vs Pertussis Vaccination during Pregnancy Scale* is a

custom-made scale tailored towards the measurement of risk perception as related to pertussis

and the pertussis vaccination recommended during pregnancy. Adapted in part from scales used in Henninger, Naleway, Cane, Donahue and Irving (226) and Wallace, Leask and Trevena (227). The scale has its bases in the severity and susceptibility elements of the Health Belief Model (249), and can be used to capture perceptions of vaccination and disease susceptibility and severity for both the mother and her baby. The scale consists of 10 statements (e.g. “*Whooping cough (as a disease) is common in my area among adults*”) that are assessed on a five-point Likert scale ranging from strongly disagree (1) to strongly agree (5). The final score is expressed as a subtraction of the vaccine related items from the disease related items with final higher values indicating a higher perception of risk related to the disease of whooping cough as compared to the vaccine. Lower values on this scale indicate a higher perception of risk for the vaccine as compared to the disease of whooping cough.

5.3.4.2 The Vaccine Confidence Scale

The *Vaccine Confidence Scale* was adapted for use in this study from a similar scale outlined in the 2014 SAGE working group on vaccine hesitancy report (250). The scale focuses on the perceived effectiveness, efficacy, importance and safety of vaccination. This scale consists of 10 statements (e.g. “*All childhood vaccines offered by the government program in my community are beneficial*”) that are assessed on a five-point Likert scale ranging from strongly disagree (1) to strongly agree (5). The final score is expressed as an average of each of the statement scores with higher values indicating greater confidence held towards vaccination.

5.3.4.3 The decision conflict scale

The *decision conflict scale* (251,252) was developed to assist in evaluating shared healthcare decisions by identifying when a patient feels stress, distress or conflict during a medical decision. In its development and testing, it was used to assess influenza vaccination decision-making. As the pertussis vaccination during pregnancy is a similar adult vaccination decision, we therefore judged this an appropriate tool for measuring decision conflict caused by a

decision to vaccinate during pregnancy. The scale has also been used previously to evaluate the effectiveness of decision aids for the MMR vaccine decision (253). This scale consists of 12 statements related to a decision (e.g. *“It’s hard to decide if the benefits are more important to me than the risks, or if the risks are more important than the benefits”*) and a separate standalone statement on intention to receive the vaccination (*“I intend to vaccinate for whooping cough during my current pregnancy”*). The 12 statements are assessed on a five-point Likert scale ranging from strongly disagree (1) to strongly agree (5), whereas the intention statement was assessed on a seven-point Likert scale also ranging from strongly disagree (1) to strongly agree (7). The final decision conflict score is expressed as an average of each statement, with higher values indicating greater levels of decision conflict. Intention to vaccinate was taken as a standalone variable with higher values indicating a higher intention to vaccinate.

5.3.4.4 Vaccine information-seeking behaviour measures

Participants were asked to report approximately how long they spent seeking information through friends and family members, through a healthcare professional and through the internet. For each of the three information channels participants were asked to select the number of hours and minutes, with zero as a possibility, they spent seeking information and the perceived influence of the information they found. A variable of total vaccine information-seeking behaviour was taken as a summation of these three questions. In the statistical analysis we took the logarithm of this total so as to meet parametric assumption.

Perceived influence of the information was measured on a seven-point Likert scale. The scale ranged from, influencing greatly away from vaccination (1) to influencing greatly towards vaccination (7), with no influence as a mid-point between the two.

5.3.5 Statistical analyses

For the purposes of analysis, the study data was downloaded from the Qualtrics servers in a comma separated values format. The data from the two surveys were linked through the use of a contact email address given by the participants at the end of Questionnaire T1 and at the beginning of Questionnaire T2. This and any additional identifiable information were subsequently deleted from the data set to preserve participant anonymity. Statistical analyses were carried out using SPSS v.24 for Windows. Power calculations were performed using the G*Power v.3.1.9.2 application (254). Each scale was scored and consolidated into variables for use in the analysis. Multiple regression models were used to test Hypothesis 1, 2 & 4 while a logistic regression was used to test Hypothesis 3.

5.4 Results

5.4.1 Outliers

To investigate our data for outliers we calculated Mahalanobis distances (MD) for the total number of hours participants spent seeking information about vaccination. Mahalanobis distance values were assessed using $X^2(4, N = 187)$ at $p < .01$. The results indicated that five values exceeded the critical value (i.e. 13.816) and were as such rejected from the analysis.

5.4.2 Predicting vaccine information-seeking behaviour (Hypothesis 1)

We performed a multiple linear regression to test if the variables *vaccine confidence*, *risk perception of vaccination during pregnancy*, *decision conflict* and *intention to vaccinate* predicted the total number of hours of vaccine information-seeking behaviour (log variable). The variables significantly predicted the total number of hours of vaccine information-seeking behaviour (log variable), $F(4, 181) = 6.597, p < .001$, and successfully explained 11.0% of the variance in vaccine information-seeking behaviour (Adjusted $R^2 = 0.110$). The variance inflation factor (VIF) for each variable indicated low multicollinearity. Table 16 presents the regression coefficients and VIF statistic for the predictor variables.

Table 16: Predictors of total time spent seeking information about vaccination (log variable). Multiple regression analysis

Variable	<i>B</i>	95% <i>CI</i>		<i>t</i>	<i>p</i>	VIF
		<i>Lower</i>	<i>Higher</i>			
Constant	2.971					
Risk perception of vaccination during pregnancy	.206	.067	.345	2.918	.004	1.828
Vaccine confidence	-.371	-.623	-.119	-2.902	.004	2.886
Decision conflict	.058	-.137	.253	.588	.557	2.033
Intention to vaccinate	-.055	-.151	.040	-1.140	.256	2.199

Two out of the four variables were found to be significant predictors of the total number of hours of vaccine information-seeking behaviour (log variable): vaccine confidence ($B = -.371$, $p = .004$) and risk perception of vaccination during pregnancy ($B = .206$, $p = .004$).

Holding a higher perception of risk towards the disease of whooping cough, as opposed to the risk of the vaccine, and having a lower confidence in vaccination were significantly associated with spending longer looking at information.

5.4.3 Predicting the perceived influence of information (Hypothesis 2)

We performed a multiple linear regression to test if the variables *vaccine confidence* ($T1$), *risk perception of vaccination during pregnancy* ($T1$), *decision conflict* and *intention to vaccinate* predict the perceived strength and direction of influence of information found through seeking. For this analysis only participants that had reported seeking information from one or more of the three information channels were included in the analysis ($n = 161$). The variables significantly predicted the perceived strength and direction of influence of information found through seeking, $F(4,160) = 3.794$, $p = .006$, and successfully explained

6.5% of the variance (Adjusted $R^2 = 0.065$). The variance inflation factor (VIF) for each variable indicated low multicollinearity. Table 17 presents the regression coefficients and VIF statistic for the included variables.

Table 17: *Predictors of perceived strength and direction of influence, of information found through seeking (multiple regression analysis)*

Variable	<i>B</i>	95% <i>CI</i>		<i>t</i>	<i>p</i>	VIF
		<i>Lower</i>	<i>Higher</i>			
Constant	-.744					
Risk perception of vaccination during pregnancy	.017	-.437	.482	.144	.886	1.912
Vaccine confidence	.022	-.222	.257	.096	.924	3.631
Decision conflict	.085	-.242	.412	.516	.607	2.008
Intention to vaccinate	.227	.053	.401	2.581	.011	2.475

One variable, intention to vaccinate, was found to be a significant predictor ($B = .227$, $p = .011$) and indicated that the greater the level of intention to vaccinate at T1 the more likely the participant was to perceive the information that they found as pointing them towards vaccination.

5.4.4 Predicting vaccine uptake (Hypothesis 3)

We performed a logistic regression to test if the variables risk perception of vaccination during pregnancy, vaccine confidence, vaccine information-seeking behaviour, intention to vaccinate and strength of recommendation from a healthcare professional predicted vaccine uptake (Table 18 shows the point-biserial correlations for variables in this analysis). A total of 173 cases were analysed and the full model significantly predicted vaccine uptake (omnibus $\chi^2 = 55.825$, $df = 5$ $p < .001$). The model accounted for between 27.6% and 64.1% of the variance in vaccine uptake, with 99.4% of vaccinating participants predicted and

71.4% of non-vaccinating participants predicted. The Hosmer and Lemeshow test indicated that the data adequately fit the model ($\chi^2 = 14.5$, $df = 8$, $p = .07$). Table 18 gives the regression coefficients and associated statistics.

Table 18: *Point-biserial correlations among variables in predicting vaccine uptake (N=173)*

Variable	Risk perception of vaccination during pregnancy	Vaccine confidence	Vaccine information-seeking behaviour	Intention to vaccinate	Strength of recommendation from a healthcare professional
Vaccine uptake	.429*	.569*	-.111	.669*	.290*

* $p < .01$

Table 19: *Predictors of vaccine uptake (binary logistic regression analysis)*

Variable	OR (Exp B)	95% CI		Wald	df	p
		Lower	Upper			
Constant	-			8.823	1	.003
Risk perception of vaccination during pregnancy	1.228	.336	4.478	0.096	1	.756
Vaccine confidence	9.460	1.15	77.78	4.369	1	.037
Vaccine information-seeking behaviour	1.756	.475	6.422	0.703	1	.402
Intention to vaccinate	1.718	.906	3.26	2.745	1	.098
Strength of recommendation from a healthcare professional	1.513	.874	2.62	2.187	1	.139

One variable, *vaccine confidence*, significantly predicts vaccine uptake. With an increase in vaccine confidence increasing the likelihood of vaccine uptake ($OR = 9.46$, $p = .037$).

5.4.5 Predicting the change in risk perception of vaccination during pregnancy (Hypothesis 4)

There was a significant difference in mean risk perception between the participants responses taken at time 1 (Questionnaire T1 $M = 1.01$, $SD = 0.90$) and the participants responses taken

at time 2 (Questionnaire T2 $M = 1.28$, $SD = 0.94$), $t(182) = 4.685$ $p < .001$. This finding indicated significantly less focus on risk associated with the vaccine (and more of a focus on risk associated with pertussis) after 36 weeks of pregnancy as compared to before 18 weeks of pregnancy. There was no significant difference in mean vaccine confidence across the two questionnaires, $t(185) = .233$ $p = .816$ (Questionnaire T1 $M = 4.00$, $SD = .73$, Questionnaire T2 $M = 3.99$, $SD = 0.76$).

We performed a multiple linear regression to test if the variables *vaccine uptake*, *total hours of vaccine information-seeking behaviour* (log variable), and *strength of recommendation* significantly predicted the difference in risk perception of vaccination during pregnancy. The variables did not significantly predicted difference in risk perception of vaccination during pregnancy, $F(3,172) = 1.118$ $p = .343$.

Table 20: *Predictors of change in risk perception (multiple regression analysis)*

Variable	<i>B</i>	95% <i>CI</i>		<i>t</i>	<i>p</i>	VIF
		<i>Lower</i>	<i>Higher</i>			
Constant	.057					
Vaccine information seeking behaviour (log)	.043	-.094	.181	.622	.534	1.045
Vaccine Uptake	-.1	-.443	.243	-.578	.564	1.134
Strength of recommendation	-.045	-.110	.02	-1.364	.174	1.111

5.4.6 Exploratory analysis of information-seeking data

88.8% of participants reported seeking additional information about vaccination, of which 91.3% reported seeking such information from friends, family members or the internet. The total hours of vaccine information-seeking behaviour variable used in the above analysis involved the summation of three common channels of vaccine information: friends and family members, a healthcare professional and the internet. Table 21 contains the perceived influence of each channel and the amount of time participants used each channel.

Table 21: Number (%) of participants by amount of time and influence of vaccine information-seeking behaviour's by channel type (N=182).

Information channel	Not used	>0 to ≤15 minutes	>15 to ≤60 minutes	>60 to ≤120 minutes	>120 minutes		
Friends and family members	49 (26.9)	76 (41.7)	46 (25.3)	7 (3.8)	4 (2.2)		
A healthcare professional	40 (22)	123 (67.6)	18 (9.9)	0 (0)	1 (0.5)		
The internet	68 (37.4)	48 (26.4)	50 (27.5)	8 (4.4)	8 (4.4)		

Information channel	Greatly away from vaccination	Somewhat away from vaccination	Slightly away from vaccination	No influence	Slightly towards vaccination	Somewhat towards vaccination	Greatly towards vaccination
Friends and family members N=133 (73.1%)	0 (0)	0 (0)	7 (5.3)	91 (68.4)	11 (8.3)	9 (6.8)	15 (11.3)
A healthcare professional N=142 (78.0%)	1 (0.7)	0 (0)	1 (0.7)	52 (36.6)	29 (20.4)	21 (14.8)	38 (26.8)
The internet N=114 (62.6%)	1 (0.9)	3 (2.6)	4 (3.5)	41 (36)	27 (23.7)	17 (14.9)	21 (18.4)

Two sections of Questionnaire T2 asked participants about their information-seeking behaviour. All participants were asked if they used any of a range of information channels. Table 22 demonstrates the frequency that each channel was used and how this differed between acceptors and decliners of the pertussis vaccination. The data lacked sufficient power to conduct Chi Squared tests to determine significant differences.

Table 22: Vaccine information-seeking behaviours conducted by participants in regards to the pertussis vaccine given during pregnancy (N=182).

Question text: “Since completing the previous survey (taken before 18 weeks of pregnancy) have you done any of the following, highlight all that apply. If none, please leave blank.”

	% of Sample (Count)	% of Acceptors (Count)	% of Decliners (Count)
<i>Used the internet to read articles or news about the whooping cough vaccine given during pregnancy (e.g. NHS Choice, Net doctor, Patient.com).</i>	45.6 (83)	43.6 (71)	66.7 (12)
<i>Used the internet to read comments or discussions from other women that have talked publicly on forums about the whooping cough vaccine (e.g. Mumsnet, Netmums, Facebook, Twitter etc).</i>	22.0 (40)	19.6 (32)	44.4 (8)
<i>Actively brought up the topic of the whooping cough vaccine given during pregnancy with your GP, Midwife, health visitor or nurse practitioner.</i>	28.6 (52)	28.2 (46)	33.3 (6)
<i>Actively brought up the topic of the whooping cough vaccine given during pregnancy with a complementary/alternative healthcare professional.</i>	5.5 (10)	4.3 (7)	16.7 (3)
<i>Actively brought up the topic of the whooping cough vaccine given during pregnancy with a religious or spiritual leader.</i>	1.1 (2)	1.2 (2)	0 (0)
<i>Actively brought up the topic of the whooping cough vaccine given during pregnancy with a friend or family member that has had past medical training.</i>	17.6 (32)	16.6 (27)	27.8 (5)
<i>Actively brought up the topic of the whooping cough vaccine given during pregnancy with a friend or family member (not medically trained).</i>	29.7 (54)	28.8 (47)	38.9 (7)
<i>Searched healthcare during pregnancy books or e-books for additional information on the whooping cough vaccine given during pregnancy.</i>	8.2 (15)	7.4 (12)	16.7 (3)
<i>Other</i>	2.2 (4)	1.8 (3)	5.6 (1)

5.4.7 Confounding variables

To check the robustness of the findings included in chapter 5 a series of sensitivity analyses were conducted using the available demographic variables that are frequently mentioned as important in previous literature. These variables included age, ethnicity, week of pregnancy when contacted for Questionnaire T1 and number of previous pregnancies (parity). Each model was run again with these additional variables and are reported in full in Appendix G. Results from these extra analysis indicate no influence of these variables in any of the models apart from a potential role of the number of previous pregnancies reducing the amount of time a participant spent seeking information ($B = -.136, p = .023$), however this result should be taken with caution due to the high p-value.

5.5 Discussion

5.5.1 Overview

In the current study, we examined the pertussis vaccine related beliefs and perceptions of pregnant women, before and after healthcare professionals typically recommend the vaccination for pertussis. We used self-reported vaccine information-seeking behaviour, during the intervening period, to examine the changes in perception that occur over the course of pregnancy, and used additional variables to predict the extent and perceived influence of such vaccine information-seeking behaviour.

One of the strongest findings in our study was that of the change in vaccine related risk perception between early and late pregnancy. A comparison across the two time points indicated an increasing perceived risk towards the disease of pertussis, as compared to the vaccine. While previous studies have indicated increased levels of disease related risk perception during pregnancy (255,256), the current study appears to be the first to record a significant change occurring between early and late pregnancy. None of the additional variables we recorded, including strength of recommendation from a healthcare professional, significantly predicted this shift in risk perception.

Vaccine information-seeking behaviour was found to play a complex role in the vaccine decision-making process. The perceived susceptibility to, and severity of pertussis, and lower levels of vaccine confidence were both associated with spending longer searching for information about the pertussis vaccine. When it came to the influence of such information, however, only intention to vaccinate significantly predicted in which direction the found information was likely to influence the participant. With higher intention to vaccinate being associated with finding information that was perceived as pointing participants towards vaccination and a lower intention to vaccinate being associated with finding information that was perceived as pointing participants away from vaccination. This form of search behaviour appears to be akin to the *confirmation bias* whereby evidence is reviewed in such a way so as to support pre-existing beliefs and expectations (257).

When separated by information channel, the positive influence of a healthcare professional becomes evident, with 62% stating that seeking information from a healthcare professional influenced them towards vaccination, what was particularly interesting however was the influence of friends and family members and the internet. When information was sought out from friends and family member's, participants largely reported no influence (68.4%). This could indicate one of two possibilities, either the information gained was not used to inform the decision-making process or it confirmed pre-existing beliefs and therefore did not move the participant in one direction or the other. As for the internet, while this channel is often cited as a detriment to vaccine uptake (158,168), the information sought through the internet overwhelming pointed participants towards vaccination (57% influencing towards compared to 7% influencing away from vaccination). This finding likely indicates the positive effects of having a strong evidence-based web presence such as that of the NHS in the UK.

5.5.2 Implications

The results of this study have a number of implications for vaccine communication. Firstly, spending additional time seeking information about vaccination outside of the healthcare professional relationship does not appear to have a negative effect on vaccine uptake. With the internet often talked about in somewhat hyperbolic terms (29,30) in the vaccine hesitancy literature it is important to note that the vast majority of people that search for information through the internet are saying that the information they found is pointing them towards vaccination. The exception would be with individuals that indicate a particularly low intention to vaccinate, internet information seeking for these individuals could potentially move them more away from vaccination. Instead, additional time with a healthcare professional for these individuals may help address their concerns.

Secondly, with the positive shift in risk perception surrounding the pertussis vaccine occurring over the course of a pregnancy if women decide earlier in their pregnancy not to get the vaccine, recommending it again later in the pregnancy may yield a different result. While the pertussis vaccine is recommended before 36 weeks of pregnancy, it is still possible for women to have it up until birth. This gives plenty of time for risk perception to change in the meantime.

Lastly, Betsch, Bodeker, Schmid & Wichmann (258) suggest that pregnancy vaccinations may be a good time to also provide information pertaining to childhood vaccinations. Seeing as a high proportion of women are active in the information gathering process guidance on appropriate sources of information at this stage would likely be highly beneficial.

With these points in mind we suggest the health bodies such as Public Health England put aside additional resources to allow extra time for women to ask questions in regards to this programme and those about childhood vaccination more generally. It is clear that women search for information about the antenatal pertussis vaccination in large numbers, so initiating

the conversation may pre-empt many of the question that mothers have. Furthermore, results from this study indicate that if mothers head into the search process with negative views regarding vaccination there is a good chance that they will come out of their search process with increasingly more negative views, so effectively communicating vaccine efficacy more generally may have additional benefits to subsequent childhood vaccination decisions.

5.5.3 Strengths and Limitations

Measuring the amount of information seeking an individual performs is an inherently difficult process. While the channels and sources of such information are important, there is also an element of subjectivity when it comes to interpreting information and a possible selection bias in who finds, consumes and applies what information to a vaccine decision. Our study design aids in researching this process and the exploratory analysis highlights some of this nuance, but much of what guides the vaccine information seeking process is left unmeasured. Foremost of these neglected areas is that of vaccine information scanning, the passive acquisition of information about vaccination which is not actively sought out. Information scanning is key to understanding the effect of vaccine information on social media and as of yet not well understood.

Due to the focus on psychological constructs many demographic factors were also largely left out of the main examination. In the past factors such as ethnicity and number of previous pregnancies have been suggested as possible antecedents to vaccine information seeking behaviour (166, 177, 219). Our additional sensitivity analysis (Appendix G) tested the influence of the additional demographic data we recorded and indicated little in the way of conclusive influence in this regard. However, one analysis did give a minor indication that the number of previous pregnancies may reduce the amount to time a participant spent seeking information about vaccination. Future research could benefit from focusing on this factor more closely.

Five outliers were rejected from our analysis, these five individuals represent those participants that searched for information about vaccination to a degree far greater than the majority of our participants. Three of these individuals include scored the lowest possible score on the *vaccine confidence* and *satisfaction with official information* scales. It would be far to say that these individuals could be classified as holding extreme anti-vaccination beliefs. The high levels of vaccine information-seeking behaviour may therefore represent a behaviour beyond merely searching for information to inform the pertussis vaccine decision and instead represents an ideological engagement with the subject of vaccination in general. The inclusion of these individuals in the analysis would have substantially skewed the results, however, with a larger sample, investigating this population may be of particular interest.

Participants in this study vaccinated at a higher rate (89.8%) than the national rate of 71.9%, indicating a possible self-selection bias related to participation and as such, caution should be taken when it comes to applying these results to those that refuse vaccination. Furthermore, owing to high statistical power, it was possible to identify small effect sizes of $d = .1$, caution therefore also recommended before placing too great a significance on the results reported in this study.

6. Synthesis

In this final chapter, I will summarise the main findings from the research studies included in this thesis (Chapters 2-5). Additionally, I discuss the strengths and limitations of the study design and how the findings of this work relate to the wider context of vaccine research and policy.

6.1 Main findings

6.1.1 Quantifying trust in vaccination

As reported in **chapter 2**, research studies specifically examining trust in vaccination are limited in number and in scope, with only 25 quantitative vaccine attitude or uptake studies explicitly exploring the concept of trust within the decision-making process. Considering the fact that the qualitative studies investigating the subject frequently cite trust as a fundamental aspect underpinning the vaccination decision-making process (131–133), this lack of quantitative investigation was a surprising revelation.

Within the same systematic review, we identified which aspects of trust these articles investigated and aimed to compare their measurement to a model of trust in vaccination that we developed through the use of the social-science literature on trust in healthcare decision-making (76–79,82). This model consisted of three, core, interrelated “levers” of trust: trust in the product of vaccination, trust in the provider of vaccination, and trust in the systems surrounding vaccination. Trust in a specific vaccine related message was assumed to be nested within the trust held across these three core levers of trust. In addition to the core levers of trust, we identified three external levers of trust in vaccination: generalized trust, historic trust and out of program influencers. We suggested that if messages from these levers align with messages from the core levers, then trust increases. If they misalign then the resilience of the core levers is tested and trust is potentially reduced or subsequently placed elsewhere.

Several of the studies reviewed touched on the healthcare system, and healthcare professional, aspects of trust. Within these studies, the link between healthcare trust, vaccine attitude and vaccine uptake appears to be a well-established finding (101,102,104–106,112,124,127). Few studies, however, examined trust in any of the additional aspects outlined in our model. Research regarding trust in scientists, the process of science, and the influence of individuals and organisations outside of the healthcare system was particularly lacking.

An additional aspect of interest was that, when studies measure trust quantitatively, many used single item measures (e.g. “*Do you trust the recommendations by the government about Vaccination?*”(117) or “*If [you] have any concerns about MMR they are taken seriously by [your] doctor*” (101)), sometimes even dichotomising the variable during analysis.

Furthermore, only three studies reported using multi-item psychometric scales of measurement (104,113,116), and only a further five studies brought in theory related to the differing aspects of trust (i.e. *social trust* and *confidence*) to design their custom questions (105,115,118,121,126).

One of the aims of our first quantitative survey study, **chapter 4**, was to investigate the influence of trust in healthcare professionals and trust in the healthcare system within the vaccine decision-making process. The findings of this study indicated that trust in healthcare professionals predicted an increased level of satisfaction in regards to the official information about the vaccine of interest. This was evidence for the form of nested trust we refer to in our model in **chapter 2**, whereby trust in the source of information relates to trust in the message that the source communicates. A similar relationship between trust and satisfaction was not present, however, for trust in the wider healthcare system itself. This potentially signals a higher level of importance to the personal relationship aspect of health communication, as compared to the perception of the healthcare system as a whole.

Counter to our hypotheses, trust did not play a role in vaccine information-seeking behaviour. We expected that a lower level of trust would lead individuals to seek more information in order to fill the gap that trust would usually bridge. While this was not found to be the case, other factors across the studies presented in this thesis have been successful in illuminating the role of vaccine information-seeking behaviour within the vaccine decision-making process.

6.1.2 The prevalence of vaccine information-seeking behaviour

Our second systematic review, as reported in **chapter 3**, aimed to examine the antecedents and consequences of vaccine information-seeking behaviour across the vaccine attitude and uptake literature. From these studies, it was evident that the propensity of active seeking for vaccine information differs across vaccination programs, with information in regards to the HPV vaccine being sought out by approximately 25% of respondents, and information in regards to childhood vaccination being sought out by around half of respondents.

Our two quantitative studies found varying rates of search behaviour for pregnant women in regards to the pertussis vaccination given during pregnancy. Our first study, **chapter 4**, indicated that 40% of participants engaged in vaccine information-seeking behaviour, while in our second study, **chapter 5**, 89% of participants engaged in vaccine information-seeking behaviour. These findings are interesting when contrasted with the findings of Campbell et al (147) from 2015.

In their study, 90% of a UK nationally representative sample stated that they “*automatically had [their] child’s immunisation when due*” as compared to only 7% that “*weighed up pros and cons of [their] child’s immunization before deciding*”. Our assumption when designing the studies in this thesis was that vaccine information-seeking behaviour was a behaviour that was being used to actively inform the pros and cons aspect of decision-making (possibly in relation to the variable of *decision conflict*). This difference in our results (i.e. many of our

participants actively sought out information), however, suggests otherwise and potentially highlights some important aspects of the behaviour we examined.

Firstly, vaccine information-seeking behaviour may not be engaged in as part of the vaccine decision-making process. Automatic vaccination may in fact be occurring with the women in my studies, with the seeking behaviour instead being more confirmatory or reassuring in nature, an aspect that we were not able to capture in the measurement that we selected.

Alternatively, our studies may have recorded less in the way of social conformity than the Campbell et al study. In their study, data collectors from Public Health England visited parents at the home and conducted their questionnaire in person. Within chapter 4, our results in regard to the psychosocial predictors of vaccine information-seeking behaviour scale indicate that participants consistently rated the items related towards the social norms (e.g. My family/friends/GP think I should look for additional information when making a vaccination decision) as disagreeing. The fact that the Campbell et al study was face to face and conducted by the health system may therefore reflect this norm in action. A norm whereby women want to seek out additional information, feel that they have the sufficient ability to do so, however feel that other (especially the healthcare professionals) would disapprove.

The location where individuals seek information about vaccination also varies greatly. In **chapter 3** we identify seven of these locations that are commonly referenced and measured in the vaccine information-seeking literature: healthcare professionals, the healthcare system, print media, broadcast media, academic media, the internet and interpersonal contacts (not including healthcare professionals). We took three of the most frequently referenced of these (healthcare professionals, the internet, and interpersonal contacts) and used them as categories in our studies to quantify the amount of time participants spend seeking

information through various information channels. In the results reported in **chapter 5**, we identified healthcare professionals as the most commonly used channel of information, however, substantially more time was spent seeking information from the internet than any other channel. We also ask more granular questions in regards to specific sub-channels of information (e.g. parenting books, social media and religious leaders) although due to the categorical nature of these and a small sample of vaccine refusers in our studies, they did not feature largely within our reported results.

6.1.3 The antecedents and consequences of vaccine information-seeking behaviour

Within the second systematic review, reported in **chapter 3**, we identified a number of preceding factors related to vaccine information-seeking behaviour. These identified antecedents can broadly be separated into social-demographic antecedents, social-cognitive antecedents and contextual factors related to information seeking. From this summarising of the literature, vaccine information-seeking behaviour appears more frequently in Caucasian individuals with higher levels of education (157,177,186,188), when seeking information is identified as a social norm (180,188), and when an individual has a child with a non-medical exemption to vaccination (in the US) (158).

The impact of seeking information from healthcare professionals, the internet and broadcast media were examined in depth across the studies included in the systematic review. As expected from our previously discussed trust and satisfaction findings, receiving information from a healthcare professional related to greatly increased positive attitude towards vaccination and vaccine uptake (48,173). This finding indicating the positive impact of seeking information from a healthcare professional was further supported by our findings in **chapter 5**. When women in this study were asked about the influence of the information they gathered, 65% indicated that the information they received from their healthcare professional moved them more towards vaccination (27% stating greatly so).

Findings from our vaccine information-seeking systematic review also indicated that, when vaccine information-seeking behaviour is taken as a binary variable (i.e. those that sought out information and those that did not), there is little in the way of a clear relationship between information-seeking and vaccine attitude or uptake. This appears to change, however, if extent of vaccine information-seeking behaviour is factored in. When done so, those that spend extensive amounts of time seeking information are more likely to have negative views towards vaccination (173,229,250). Within our analysis, therefore, we were conscious not to treat vaccine information-seeking behaviour as a binary variable. Instead we measured the amount of self-reported time that participants spent seeking information.

Within the study presented in **chapter 5**, we identified a significant predictive relationship between vaccine hesitancy/confidence, risk perception of vaccination during pregnancy and the amount of time that participants spent searching for information. A higher perception of risk towards the disease of pertussis and a lower level of vaccine confidence (both prior to the decision to vaccinate being prompted) were both individually associated with spending longer seeking out information about the vaccine during pregnancy. This finding is potentially capturing two different types of vaccine information-seeking behaviour. The first being a form of threat prevention behaviour as outlined by motivation protection theory (259), with prior perceptions of pertussis as a risky disease prompting a higher level of protective behaviours. In this case, the protective behaviour involved seeking additional information in order to protect against the disease of pertussis. The second type of vaccine information-seeking behaviour could reflect a more reactionary behaviour in regards to a recommendation that is counter to pre-existing vaccine hesitant beliefs, with participants low in vaccine confidence searching extensively to “disprove” a recommendation or social norm. This can also be seen as evident in the finding that those with a lower intention to vaccinate

prior to the prompting of the vaccine decision were more likely to find information that pointed them away from vaccination.

6.2 Methodological considerations and limitations

Across this thesis I designed four studies to investigate the role of vaccine information-seeking behaviour in relation to the vaccine decision-making process. Broadly speaking, all studies were designed during 2015/16, the trust in vaccination systematic review (**chapter 2**) was conducted during the administration of the survey study reported in **chapter 4** (2016/17), and the vaccine information-seeking behaviour systematic review (**chapter 3**) was conducted during the administration of the survey study reported in **chapter 5** (2017/18). As such, some of the lessons learnt throughout the course of this work were not as effectively incorporated into the quantitative research as would have been preferred.

Most key of these absences was the modelling and prominence of trust within the two quantitative survey studies. While psychometric measures of trust were incorporated into the survey design, the inclusion of aspects of trust beyond the healthcare system and healthcare professionals would have brought the study more in line with the *trust in vaccination* model we developed for the systematic review in **chapter 2**. Furthermore, a split between *confidence* and *social trust* in the measurement of trust in a healthcare professional would have allowed for an enlightening comparison between the concepts across the two measured aspects of trust and potentially more meaningful findings.

An additional trust aspect that we identified later in the research process was the problematic measurement of trust in a healthcare professional due to the changing of healthcare professionals that sometimes occurs during the course of normal interaction with the healthcare system. When trust is lost in an assigned healthcare professional, people may change to a healthcare professional that they trust more, to the extent that an individual outside of the mainstream healthcare system may be seen as someone's primary healthcare

professional and reported levels of trust in this individual may be high (if not higher) than a healthcare professional from the healthcare system. This nuance is lacking within the way we quantified trust in **chapter 4** and is another example of why measurement of wider aspects of trust would have been beneficial.

Similar quantitative issues were present in the measurement of vaccine information-seeking behaviour and the distinction between sources of information and channels of information.

For instance, information seeking from a “primary healthcare professional”, with this phrasing, refers to a *channel* of information rather than a *source* of information. A *source* here would be the specific healthcare professional that the participant sees during the course of their pregnancy, where there is obviously a great deal of variability. This distinction may seem trivial, however, it makes findings such as the 1.4% of people that were pointed more away from vaccination after seeking information from their healthcare professional difficult to interpret. Were these individuals victim to a backfire effect whereby pro-vaccination information that conflicts with their beliefs pushes them further away from vaccination (260)? Or did their healthcare professional explicitly advise against the vaccination? There is no way of knowing this given the way that this variable was measured. The only conclusion that can be drawn here is that, as a whole, the channel of a *primary healthcare professional* moves people more towards vaccination. This distinction becomes more problematic when the channel of information is *the internet*. While *the internet* can certainly be referred to colloquially as a source of information it is more appropriate to refer to it as a channel of information. This is due to the fact that someone having “used the internet” to seek information about vaccination could refer to the accessing of a spectrum of resources, from reading peer reviewed articles, to watching a video in which a parent tells an emotional story about how they believe their child suffers from a developmental disorder due to vaccination. While this issue does not compromise the findings related to the extent of time spent

searching for information, with hindsight more distinction within the internet as a channel of information would have been useful.

Chapter 3 identified a range of social demographic characteristics that have preceded vaccine information-seeking behaviour. While these factors were not the main focus of this line of research including them in the planning stages as possible confounding variables could potentially have added additional depth to our results. Key among the previously documented demographic variables of interest were socio-economic status and educational attainment (158, 170, 186, 198), each of these have proven important variables when examining information and may have been useful in explaining additional variance in our models.

According to the variables we did check for as possible confounders the number of previous pregnancies (parity) was identified as potentially playing a role in vaccination information-seeking behaviour. This is understandable, especially when it comes to a new vaccination programs such as an antenatal vaccination programme. If the vaccine programmes are introduced poorly then it might look to the mother as if “the science” keeps changing, with mothers thinking that during last pregnancy this was not recommended, why now? As such framing new vaccine as a way to better protect a baby, rather than the recommended practice merely changing is an important distinction.

A further limitation across this thesis involves the sampling process utilised for the two survey studies (**chapter 4 & 5**). These studies both required a specialist sample of either women that had a child during the previous six months (**chapter 4**) or women that were between 4 and 18 weeks of pregnancy (**chapter 5**). Across both studies approximately 5000 baby and pregnancy community groups, across England and Wales, were identified through the local listings on the website www.netmums.com. The organisers of these groups were contacted and asked to share a hyperlink to the surveys with their group members.

While this method allowed for a large, nationally representative, specialist sample on a limited budget, it also likely enabled a number of unintended biases in participant recruitment. The reliance on local group organisers to spread our recruitment message added an additional barrier to entry for the studies. While an effort was made to make the invitation as neutral as possible it may have been the case that, at the group level, there was a non-random refusal to share the advert based on the group leaders' attitude towards vaccination. If for example group leaders are more likely to have positive views towards vaccination, and group members shared similar views, then this could have led to a lower proportion of participants that were opposed to vaccination. An equal effect may have also occurred with those group leaders that were particularly pro-vaccination, with them talking particularly enthusiastically about the research and encouraging higher participation from their group members. This self-selection bias, while not visible geographically, may potentially explain the high uptake rate within the studies. In the study reported in **chapter 4** uptake of the vaccine was 94.9% and in **chapter 5** uptake was 89.6%. This compared to national uptake of approximately 70% across this time period (261).

More generally, while care was taken not to explicitly prime participants to the subject of our studies, it was obvious when stating the questionnaires that the study was about perceptions towards vaccination. In the study reported in chapter 5, as previously mentioned, vaccination rates were high and this could have been due to selection bias, however another alternative explanation could be that enrolment in the study itself changes the behaviour more towards uptake seeing as they were told that another questionnaire was going to occur near the end of their pregnancy. An additional control group at Time 2 that did not participate in the Time 1 questionnaire may have been an important addition in retrospect.

Finally, recall bias may have been an issue across the studies, especially for the study reported in chapter 4. The sample within this study were *'mothers that had given birth during*

the last six months’, since the first six month with a new baby can be particularly disruptive, it can be expected that specific details regarding a decision made during pregnancy may not be easily remembered. Furthermore, if the parent was currently vaccinating their young infant this may have retrospectively shaded how they perceived their various information behaviours and influence of information they received during pregnancy.

6.3 Research and Programme Implications

Some of the findings presented in this thesis are directly relevant to future vaccine decision-making research and to the current UK pertussis during pregnancy vaccination programme.

6.3.1 Future measurement of trust in vaccination

One of our recommendations from the trust in vaccination systematic review (**chapter 2**) was for quantitative researchers to develop and make use of a simple two item scale that makes the distinction between competency (the performance aspect of trust) and shared values (the *social trust* or morality aspect of trust) when investigating trust in channel of vaccine information.

When measuring aspects of trust in vaccination, questions with this form of framing would allow for a diagnosis of whether deficits in trust are due to system/administrative issues (i.e. lacking in *confidence*), or whether public perception has shifted to the point where the public view institutions as having goals opposed to their desires (i.e. lacking in *social trust*). Future research could thus investigate potential responses to trust erosion based on such a distinction. My cautious assumption here is that there could be specific responses that are more suitable to a lack of *confidence*, for example the assessment/education of healthcare professional’s knowledge, and others that would be more suitable to a lack of *social trust*, for example the corrections of myths present within the wider public.

Expanding the scope of existing trust research is also of interest. As identified in both of our systematic reviews few studies have investigated trust in vaccination or vaccine information-

seeking behaviour in low- and middle-income countries. A recent study by The Wellcome Trust explored the relationship between trust and vaccination on a global scale with their Global Monitor survey (262). This survey measured a number of the related aspects within the vaccine decision-making process such as trust and understanding of science and health information-seeking behaviour. While the previous *State of Vaccine Confidence* studies from The Vaccine Confidence Project™ (based at The London School of Hygiene & Tropical Medicine) from 2015 and 2018 (4,263) have looked at attitudes towards vaccination these studies did not investigate the surrounding aspects of trust in the healthcare system and other related institutions. Within the Wellcome Global Monitor survey these wider aspects are starting to be examined and, as identified in our systematic review, are found to be key to the vaccine decision-making process. Within their questions pertaining to trust they have even made a slight distinction between *confidence* and *social trust* aspects of trust in science/scientists. More emphasis on these aspects of measurement could potentially identify the nuances in the current trends of vaccine hesitancy if similar surveys are re-administered on this scale in the future.

6.3.2 The internet and vaccine information seeking behaviour

A great deal of the current public discourse in regards to vaccine decision-making, specifically vaccine refusal, has focused on the role the internet plays in information acquisition. Due to the nature of the internet, however, this area of study is in a near constant state of flux. Google regularly makes changes to its algorithm, sometimes with an explicit aim to make the results of health queries more reliable (265). Facebook, twitter and YouTube have also recently made similar moves to improve the reliability of their search functions and mitigate the organic reach of anti-vaccination content on their platform (266). As such, caution should be taken with the use of any of the previous academic examinations of the internet as a channel of vaccine information. For example, studies have previously

documented the results of various search terms on google (17,168,204,205,210) and the extent of vaccine information on various social media platforms (20-23,25,28,212). While this research is useful for highlighting the extent and prominence of anti-vaccination information at a specific time, their findings rarely stay relevant for long and explain little when it comes to the effect that such information is having on existing vaccination programmes. A potentially more useful line of research going forward would be to examine how people curate their own personal range of trusted sources that they draw from (their *information field*) and how the internet helps facilitate such acquisition, possibly amplifying the beliefs that are already present.

To this point, my results from **chapter 5** indicate that spending additional time seeking information about vaccination outside of the healthcare professional relationship does not appear to have a negative effect on vaccine uptake, and in fact the vast majority of people that search for information through the internet said that the information they found pointed them more towards vaccination. The exception here is with individuals that already indicate a particularly low intention to vaccinate. As a consequence, online enquiry can be recommended for individuals that are “on the fence” about vaccination, while those with more intractable vaccine hesitant beliefs are likely best advised by a trusted healthcare professional that can adapt more fluidly to questioning and as such avoid the confirmation bias that can exist when seeking information online.

6.3.3 Pertussis vaccination during pregnancy

The programme to vaccinate women against pertussis during pregnancy is largely perceived positively by the women whose data form this thesis, with less than 1 in 10 women rejecting the vaccine and few holding strong vaccine hesitant beliefs.

In our first survey (**chapter 4**), we found that trust in a primary healthcare professional, adopting a problem-focused engaged strategy when coping with general stressful event, and high perceived behavioural control in own vaccine information-seeking behaviour, were all related to the satisfaction felt towards official information about the pertussis vaccine. As such, satisfaction can be seen as being nested within the trust relationship and the ways in which the women engage with a decision. This finding can potentially be seen as demonstrating the importance of shared decision-making within the vaccine decision-making process. Often shared decision-making can be seen as counterproductive when vaccination is concerned, due to the highly rigorous evidence base from which vaccination recommendations are made. However, through such discussions, relationships can be deepened and self-efficacy to engage with the decision can be improved.

Another pregnancy specific finding from our studies was the positive shift in risk perception surrounding the pertussis vaccine that was found to occur over the course of a pregnancy (**chapter 5**). While none of the variables we analysed predicted this improvement, it is likely that this is due to the process of preparation for parenthood that parents to be undertake during this time (219,264). The fact that such a change occurs during pregnancy suggests that perceptions towards vaccines can be subject to change over a relatively short period of time. With more resources it would have been interesting to explore this change further. Some avenues of research that were underpowered in our research, but that would be of value if conducted, were the perceptions of women during their first pregnancy or women that had a pregnancy prior to the introduction of the pertussis vaccination program. The former may be more willing to vaccinate, due to higher levels of dependency on their healthcare professional during their first pregnancy, while the latter will have seen a change in policy across their pregnancies and might in future pregnancies be somewhat apprehensive to the new vaccine.

7. Conclusion

In recent decades, people in high income countries have moved from an environment of vaccine-information scarcity to an environment of vaccine-information abundance. People in these countries are no longer required to solely dependent on their local doctor, family or friends for advice in regards to vaccination, but instead now have the option of supplementing these sources with information that they gather through a range of trusted online sources. Since the advent of the internet, vaccine information, of varying levels of reliability, have become more readily available to the general public. With the further advent of social media people can also be readily exposed to such information through their social network even without the behaviour of active search. As such vaccine decision-making can now be seen to occur within a largely uncontrolled information environment, where any number of sources can be consulted and vaccine misinformation is only ever a few button presses away.

The results reported across this thesis demonstrate the influence of vaccine information-seeking behaviour within the vaccine decision-making process. This seeking of information about vaccination, in and of itself, is not detrimental to vaccine uptake, but instead the location and extent of such seeking contributes to the held beliefs that play a substantial role in informing a vaccination decision. Trust is a key factor in the use of a source for vaccine information. If trust in a source is held then the source works as a conduit for the message that they provide. This can be seen to be most evident when the trusted source of vaccine information is a healthcare professional, with a high level of trust correlating with satisfaction felt towards the information they provide. When beliefs related to the pertussis during pregnancy vaccination are examined across pregnancy, extensive vaccine information-seeking behaviour is associated with an increased focus being placed on the risk of pertussis, as compared to the pertussis vaccination, and a lower overall confidence in vaccination is

reported. A further understanding of the cyclical process whereby an individual continually shapes their unique range of sources from which vaccine messages are drawn from is key to the further understanding vaccine hesitancy.

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Clarke, R. M., Sirota, M., & Paterson, P. (2019). *Do previously held vaccine attitudes dictate the extent and influence of vaccine information-seeking behavior during pregnancy?*. *Human vaccines & immunotherapeutics*, 15(9), 2081-2089. <https://www.tandfonline.com/doi/full/10.1080/21645515.2019.1638203>

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From: Tim Earle <tcearle@gmail.com>
Sent: 03 July 2019 15:55:16
To: Richard Clarke
Subject: Re: [Understanding Social Trust] Contact

Dear Mr. Clarke,

I happily grant you permission to use an image of the TCC Model in your PhD thesis. I would also be happy to receive a copy of your thesis.

Thank you for your interest in the TCC Model.

Best wishes,

Tim.

On Wed, Jul 3, 2019 at 6:39 AM Richard Clarke <donotreply@wordpress.com> wrote:

Your Name: Richard Clarke

Your Email: Richard.clarke@lshtm.ac.uk

Subject: Seeking permission to use image in thesis

Comment: Dear Dr Earle,

I will soon be submitting my PhD thesis. I intend to make this open access through our university thesis depository. Within the thesis I include the simplified version of your TCC Model and as such I am seeking permission to use the image you've created in my thesis (with the appropriate reference, obviously).

If you require the context for this please let me know and I would be more than happy to send you a copy of my thesis.

Kind regards,

Richard

From: Tim Earle <tcearle@gmail.com>

Sent: 06 July 2019 20:25:59

To: Richard Clarke

Subject: Re: [Understanding Social Trust] Contact

Dear Richard,

I've taken a quick, preliminary scan of the articles and draft thesis you sent, and I'm just blown away by the quality and quantity of the work you have done on trust-related issues. Of course, I'm particularly impressed and grateful for your insistence (if that's not too strong a word) on the distinction between trust and confidence, a difference that many researchers fail to grasp, but which I believe is basic.

Beyond the fundamental conceptual issues, it's equally impressive that you have applied (what I believe to be) the most useful framework for understanding trust-related issues to a highly significant social problem.

Seems to me that a lot of good could come out of this!

Congratulations!

Tim.

On Thu, Jul 4, 2019 at 2:11 AM Richard Clarke <Richard.Clarke@lshtm.ac.uk> wrote:

Dear Dr Earle,

Wonderful, thank you for this. See attached for a (near) final draft of the thesis and two of the published papers from this project.

I really appreciate the extra effort you took outlining your work on your website. My PhD is quite interdisciplinary so there's a chance that I wouldn't have come across it through literature reviews otherwise.

Best wishes,

Richard

Appendix B: Supplemental materials for chapter 2 systematic review

Recorded effects of trust on vaccine uptake

Ref.	Definition of trust	Aim of study/Research question	Questions included to measure type of trust	Social capital/General trust	Trust in HCS	Trust in HCP	Trust in government
Casiday R, Cresswell T, Wilson D, Panter-Brick C. A survey of UK parental attitudes to the MMR vaccine and trust in medical authority. <i>Vaccine</i> . 2006 Jan 12;24(2):177-84	Slight distinction made between trust and confidence although this theme was not explicitly expanded on when explaining the development of measure. Questions themselves hint towards the distinction of shared values and competence	Trust featured in one of the 4 study aims. <i>“To determine the level of agreement, among both MMR-accepting and MMR-refusing parents in a PCT population, with statements about (a) the safety of MMR vaccine, (b) single-antigen vaccines, (c) the importance of immunisation, and (d) trust in medical authority.”</i>	Single item measuring distrust in HCS: <i>“Doctors are too dismissive of what parents claim about vaccine side effects”</i> Single item measuring trust in HCP: <i>“If I have any concerns about MMR they are taken seriously by my doctor”</i> Single item measuring trust in government: <i>“The Government would stop the MMR if there was evidence of a serious risk”</i> Measurement was on a 4 point Likert scale (Strongly agree/Agree/Disagree/Strongly disagree)	Not assessed	(Distrust) Positive association with vaccine refusal ($p<0.001$)	Positive association with vaccine uptake ($p<0.001$)	Positive association with vaccine uptake ($p<0.001$)
Cheng PJ, Huang SY, Shaw SW, Kao CC, Chueh HY, Chang SD, Hsu TY, Kung FT. Factors influencing women's decisions regarding pertussis vaccine: A decision-making study in the Postpartum Pertussis Immunization Program of a teaching hospital in Taiwan. <i>Vaccine</i> . 2010 Aug 2;28(34):5641-7.	Trust was not explicitly defined	Trust featured within aims of study. <i>“The aims of this study were to explore factors that influenced postpartum women's decisions regarding pertussis vaccination and to determine if women's concerns about vaccine safety and efficacy were related to their information needs and trust in the content of information provided, or both”</i>	Single item measuring trust <i>“Do you trust the information in the document ‘About pertussis vaccine- Calling all Moms’?”</i> Measurement using binary yes/no	Not assessed	Positive association with vaccine uptake ($p<0.01$, OR of 6.1, CI 3.8-9.3)	Not assessed	Not assessed
Das J, Das S. Trust, learning, and vaccination: a case study of a North Indian village. <i>Social Science & Medicine</i> . 2003 Jul 31;57(1):97-112.	Trust was not explicitly defined	Trust not explicitly mentioned in a research question but formed one of main examined relationships. <i>“we examine the relationship between community knowledge regarding vaccination and community trust in</i>	Not reported	Not assessed	Not assessed	No association found with vaccine uptake	Not assessed

		<i>the provider of vaccinations, and show how these two factors jointly determine the demand for preventive health services."</i>					
Fowler GL, Baggs JM, Weintraub ES, Martin SW, McNeil MM, Gust DA. Factors influencing laboratory workers' decisions to accept or decline anthrax vaccine adsorbed (AVA): results of a decision-making study in CDC's anthrax vaccination program. <i>Pharmacoepidemiology and drug safety</i> . 2006 Dec 1;15(12):880-8.	Trust was not explicitly defined	Trust featured within aims of study. <i>"The purpose of this study was to determine (1) the factors that influenced laboratory workers' decisions to accept or decline AVA, and (2) if laboratory workers' concern about AVA safety was related to their information needs and trust in the information provided"</i>	Single item measuring trust: <i>"Do you trust the information in the document 'Anthrax Vaccine-What you need to know'?"</i> Measurement using binary yes/no	Not assessed	Positive association with vaccine uptake ($p<0.01$ OR 2.3, CI 1.1-4.5)	Not assessed	Not assessed
Fu LY, Zimet GD, Latkin CA, Joseph JG. Associations of trust and healthcare provider advice with HPV vaccine acceptance among African American parents. <i>Vaccine</i> . 2017 Feb 1;35(5):802-7.	Trust was not explicitly defined	Research question not explicitly mentioned but trust features prominently within main examined relationships. <i>"The current study examined the dual associations of parental trust in HCPs for vaccine advice and strength of HCP vaccination recommendations with HPV vaccine acceptance among African American parents"</i>	Single item measuring trust in HCS: <i>"How much do you trust websites from doctor groups like the American Academy of Pediatrics?"</i> Single item measuring trust in HCP: <i>"How much do you trust your child's doctors, nurses or other healthcare providers?"</i> Single item measuring trust in government: <i>"How much do you trust government websites like the Centers for Disease Control and Prevention, also called the CDC?"</i> Measurement allowed three response options (None/Some/A lot)	Not assessed	No association found with vaccine uptake	Positive association with vaccine uptake ($p<0.001$, adjusted OR = 2.3, CI 1.1-4.8)	Positive association with vaccine uptake ($p<0.01$)
Gilles I, Bangerter A, Clémence A, Green EG, Krings F, Staerklé C, Wagner-Egger P. Trust in medical organizations predicts pandemic (H1N1) 2009 vaccination behavior and perceived efficacy of protection measures in the Swiss public. <i>European journal of epidemiology</i> . 2011 Mar 1;26(3):203-10.	Trust in the context of compliance (cooperation) with official recommendations mentioned. Previous vaccine crises mentioned in introduction in the context of competence related trust.	Research question not explicitly mentioned but trust features prominently within main examined relationships. <i>"Trust in medical organizations measured among Swiss residents in the Summer of 2009 is the only variable that predicts actual vaccination status during the Winter 2009 pandemic (H1N1) 2009 vaccination campaign"</i>	Three items measured trust in government. Three items measured trust in medical organizations. Items measured on a 5 item Likert scale (Low=1, High=5) Specific questions were not reported.	Not assessed	Significantly predicted vaccine uptake in regression model ($B=.76$ SE=.21 $p<.001$ OR = 2.14)	Not assessed	Did not significantly predict uptake in regression model

Kolar SK, Wheldon C, Hernandez ND, Young L, Romero-Daza N, Daley EM. Human Papillomavirus Vaccine Knowledge and Attitudes, Preventative Health Behaviors, and Medical Mistrust Among a Racially and Ethnically Diverse Sample of College Women. J racial Ethn Heal disparities. 2015;2(1):77–85.	Trust was not explicitly defined	Trust features within study hypothesis. <i>“We hypothesized that higher mistrust and greater difficulty talking to health-care providers (HCPs) would be associated with lack of preventative health behaviors in this population”</i>	Group-Based Medical Mistrust Scale (Shelton, Winkel, Davis, Roberts, Valdimarsdottir, Hall & Thompson 2010)	Not assessed	Women with higher mistrust were less likely to have engaged in preventative health behaviors such as HPV vaccination	Racial concordance between HCP and respondent played a significant role	Not assessed
Lee C, Whetten K, Omer S, Pan W, Salmon D. Hurdles to herd immunity: Distrust of government and vaccine refusal in the US, 2002–2003. Vaccine. 2016 Jul 25;34(34):3972-8.	The definition of trust was, while not explicit, were touched on through the use of terms such as beneficence, equity, and openness of information	Trust forms the main findings of the study. <i>“These data offer the potential to illuminate how distrust contributes to vaccine hesitancy and vaccine refusal in parents of school-aged children by looking at questions including where parents get their vaccine information, whether they use complementary/alternative medicine (CAM) practitioners, and how they feel about immunization requirement laws.”</i>	Trust in health care providers Used an adapted version of the trust in physician scale (Anderson and Dedrick 1990) Measurement was on a 5-Point Likert Scale (end points: 1 = strongly disagree, 5 = strongly agree) Trust in government (scale constructed for study) 1. Does everything it should to protect the things that are important to me 2. Is partly responsible for the illegal drug problems in this country 3. Was responsible for creating HIV and AIDS 4. Is more concerned about people who are rich than those with less money 5. Is more concerned about some racial and ethnic groups than other groups Measurement was on a 5-Point Likert Scale (end points: 1 = strongly disagree, 5 = strongly agree) Constructs were scored by taking an average of each scale.	Not assessed	Not assessed	Distrust in HCP was positively associated with not vaccinating child fully ($p < 0.01$, OR = 1.97 CI 1.45-2.67)	Distrust in government was positively associated with not vaccinating child fully ($p < 0.01$, OR = 1.97 CI 1.45-2.67)

			Later dichotomised into trust/distrust				
Manika D, Ball JG, Stout PA. Factors Associated with the Persuasiveness of Direct-to-Consumer Advertising on HPV Vaccination Among Young Women. Journal of health communication. 2014 Nov 2;19(11):1232-47.	Trust literature in introduction makes reference to reducing uncertainty and perceived risk.	Trust featured in one of the 4 study research questions. <i>"How do traditional consumer factors (knowledge, familiarity, attitudes, and trust of direct to consumer advertising for a brand of the HPV vaccine) differ between those who have and have not received the vaccine?"</i>	Single item measuring trust in direct to consumer advertising. 7 point Likert scale. Item not reported.	Not assessed	Significantly predicted uptake ($B=-.555$, $p<0.01$) Only significant predictor	Did not significantly predict uptake regression model. Significant association with vaccine uptake $p<0.05$	Not assessed
Rönnerstrand B. Social capital and immunisation against the 2009 A (H1N1) pandemic in Sweden. Scandinavian Journal of Social Medicine. 2013 Dec;41(8):853-9.	Social capital/ generalized trust definition and literature reported.	Research question not explicitly mentioned but trust features prominently within main examined relationships. <i>"The current paper investigates the association between contextual state-level generalized trust and individual 2009 A(H1N1) pandemic immunization in the American states"</i>	Single item measuring generalized trust: <i>"According to your view, to what extent is it possible to trust people in general"</i> Measurement was on a 10-point Likert scale (end points: 1= it is not possible to trust people in general, 10=it is possible to trust people in general)	Positive associated with vaccine uptake (OR 1.274, CI 1.018-1.594)	Not assessed	Not assessed	Not assessed

Recorded effects of trust on intention to vaccinate

Ref.	Definition of trust	Aim of study/Research question	Question included to measure type of trust	Trust in HCS	Trust in HCP	Trust in government	Generalized trust
Chuang YC, Huang YL, Tseng KC, Yen CH, Yang LH. Social capital and health-protective behavior intentions in an influenza pandemic. PLoS One. 2015;10(4):1–14.	Social capital/ generalised trust definition and literature reported	Trust featured within study hypothesis. <i>"The hypothesis proposed was that each component of social capital—bonding, bridging, and linking—contributed to a person's intent to receive a vaccine, wear a face mask, and wash hands more frequently during an outbreak of influenza pandemic."</i>	Three items measured different aspect of social capital. Items were not reported however an outline of each was given. 1. The number of neighbours with whom the respondent was on greeting terms Measurement allowed five options (0, 1-4, 5-9, 10-29 and ≥ 30) 2. The number of neighbours from whom the respondent could ask a favour when needed, such as receiving a mail delivery and taking care of or picking up children Measurement allowed five options (0, 1-2, 3-4, 5-9 and ≥ 10)	Not assessed	Not assessed	General government trust positively associated with intention to vaccinate (OR = 1.39, CI 1.21 – 1.60) $p<.01$ No association with trust in governments capacity to handle an influenza pandemic	Neighbourhood support positively associated with intention to vaccinate (OR = 1.17, CI 1.05-1.31) $p<.01$ No association with memberships in associations

			<p>3. Bridging social capital was measured by asking respondents to indicate membership in any association</p> <p>Measurement allowed two options (Yes and No)</p> <p>Two items measured trust in government. Items were not reported however an outline of each was given.</p> <ol style="list-style-type: none"> 1. General government trust was measured by asking the respondents to assign separate ratings to the central government, local government, and township administrative offices 2. Respondents evaluated whether the government fully informs the public with information regarding new types of influenza, whether they worry that the government might hide information about a new type of influenza, and whether they think that the government has the ability to manage an epidemic immediately if a new type of influenza occurs in Taiwan. <p>Measurement was on a 5-point Likert scale. (end points not reported)</p>				
Marlow LA, Waller J, Wardle J. Trust and experience as predictors of HPV vaccine acceptance. Human vaccines. 2007 Sep 1;3(5):171-5.	<p>Trust was not explicitly defined.</p> <p>Questions themselves hint towards the distinction of shared values and competence</p>	<p>Trust featured within aims of study.</p> <p>“To examine the association between general vaccine attitudes, trust in doctors and the government, past experience with vaccination, and acceptance of HPV vaccination”</p>	<p>Single item measuring distrust in HCS: <i>“Doctors are too dismissive of what parents claim about vaccine side effects”</i></p> <p>Single item measuring trust in HCP: <i>“If I have any concerns about MMR they are taken seriously by my doctor”</i></p> <p>Three items measuring trust in government:</p> <ol style="list-style-type: none"> 1. <i>“The government is too defensive about MMR”</i> 2. <i>“The government would stop vaccination if there was evidence of a serious risk”</i> 3. <i>“The government does a good job of protecting us from risks to health”</i> 	Positive association with intention to vaccinate (OR = 1.35, CI 1.22-1.50)	Assessed and reported as a combined factor with trust in government	Positive association with intention to vaccinate (OR = 1.70, CI 1.23-2.36). Analysis within this study combined Trust in HCP and Trust in government into one factor	Not assessed

			Measurement was on a 4 point Likert scale reduced to two points for analysis (Agree/Disagree)				
Scherer LD, Shaffer VA, Patel N, Zikmund-Fisher BJ. Can the vaccine adverse event reporting system be used to increase vaccine acceptance and trust?. Vaccine. 2016 May 5;34(21):2424-9.	Trust was not explicitly defined. Questions however hint towards measuring (1) confidence and two (2) social trust.	Research question not explicitly mentioned but trust features prominently within main examined relationships. <i>"In this study, we tested the possibility that open communication about VAERS – how it works, what it is for, and what the database contains – could improve trust in the accuracy and honesty of the CDC's conclusions about vaccine safety and increase vaccine acceptance by concretely illustrating how few adverse events occur compared to the number of vaccinations given, as well as highlighting the CDC's efforts to monitor and document possible harms."</i>	Two items measuring trust in HCS 1. <i>"Do you trust the CDC's conclusions that the HPV vaccine is safe?"</i> 2. <i>"Do you believe that the CDC is faithfully reporting the risks of the HPV vaccine?"</i> Measurement was on a 6-point Likert scale (end points: 1= not at all, 6=very much so)	Experimental study. Findings indicated that showing a summary of the VAERS data slightly increased acceptance and trust however detailed reports greatly reduced acceptance and trust.	Not assessed	Not assessed	Not assessed
Taylor-Clark K, Blendon RJ, Zaslavsky A, Benson J. Confidence in crisis? Understanding trust in government and public attitudes toward mandatory state health powers. Biosecurity and bioterrorism: biodefense strategy, practice, and science. 2005 Jun 1;3(2):138-47.	Introduction outlines the distinction between social trust and confidence in the context of risk perception. Definition is reflected in the two questions used (1) confidence (2) social trust.	Research question not explicitly mentioned but trust features prominently within main examined relationships. <i>"In this study we analyse a recent survey to determine the effects of a set of variables, including aspects of trust in government that have been found in previous studies to influence public opposition to compulsory government health policies, on opinions about compulsory vaccination and quarantine."</i>	Seven items measuring trust. Only two example items given: 1. <i>"If an outbreak of smallpox occurred, how prepared do you think your local health department would be to prevent smallpox from spreading?"</i> 2. <i>"If an outbreak of smallpox occurred and not everyone could get vaccinated quickly, do you think [African Americans/the elderly] would be discriminated against when it comes to getting [wealthy and influential people would get vaccinated first], or would they treated like everyone else?"</i> Measurement was on a 4 point scale reduced to two points for analysis (Likely/Unlikely)	Positive association with being in favour of compulsory vaccination policy (p<0.05, OR=1.415, CI 1.03-1.943) OR in favour of vaccination policy OR vaccine opposition to compulsory vax 1.728 (1.166-2.560)	Not assessed	Not assessed	Not assessed
Tucker-Edmonds BM, Coleman J, Armstrong K, Shea JA. Risk perceptions, worry, or distrust: What drives pregnant women's	Trust was not explicitly defined.	Trust featured in one of the 2 study aims. <i>"the primary aim of this study is to assess pregnant women's risk</i>	The health care system distrust scale (Shea, Micco, Dean, McMurphy, Schwartz & Armstrong 2008)	(Distrust) Positive association with intention to refuse vaccine (p<0.001,	Not assessed	Not assessed	Not assessed

decisions to accept the H1N1 vaccine?. Maternal and child health journal. 2011 Nov 1;15(8):1203-9.		<i>perceptions, worry, and health care distrust in relation to the H1N1 pandemic flu and the H1N1 flu vaccine; and to determine if these factors relate to the mothers' intentions to receive the vaccines "</i>		Adjusted OR 0.53 however p=0.10			
van der Weerd W, Timmermans DR, Beaujean DJ, Oudhoff J, van Steenberg JE. Monitoring the level of government trust, risk perception and intention of the general public to adopt protective measures during the influenza A (H1N1) pandemic in the Netherlands. BMC public health. 2011 Jul 19;11(1):575.	Trust defined with the Trust and confidence Model (earle, Siegrist & Gutscher 2010). Definition reflected in measures of relational trust and confidence.	Trust featured in two of the 3 study aims. <i>"The aim of the study was to identify and describe possible changes in the public's level of government trust, risk perception, and intention to adopt protective measures. Secondly, we wanted to identify whether government trust and risk perception were positively associated with an intention to adopt protective measures, including vaccination. "</i>	Five items measuring trust. Items informed by the Trust and Confidence Model (Earle, Siegrist & Gutscher 2010). Three items measured relational trust: <ol style="list-style-type: none"> 1. During a major crisis, the government informs you about the concerned crisis. How much trust do you generally have in information provided by the government about the Mexican flu? 2. How much trust do you have in measures already taken by the government against the Mexican flu? 3. How much trust do you have in the government with respect to fighting the pandemic? Two items measured confidence: <ol style="list-style-type: none"> 1. What do you think of the decisiveness of the government in taking safety measures against the Mexican flu in the Netherlands? 2. How much trust do you generally have in the government, irrespective of crisis management? Measurement was on a 4 Point Likert Scale (end points: 1= no trust, 4=High level of trust)	Not assessed	Not assessed	Trust in Gov significantly decreased as the pandemic continued p<0.001 Trust in Gov increased the likelihood of an intention to accept vaccination (p<0.05, OR 1.05) However, trust in Gov decreased the likelihood of intention to adopt protective measures (p<0.01, OR 0.92) early in the pandemic only.	Not assessed

Factors associated with trust

Ref.	Aim of study/Research question	Question included to measure type of trust	Trust in HCS	Trust in HCP	Trust in government	Trust in out of program influencers	Generalized trust
Berry JG, Gold MS, Ryan P, Duszynski KM, Braunack-Mayer AJ, Vaccine Assessment Using Linked	Trust features in the main examined factors	Not reported	Respondents in this survey who voiced concerns about the likelihood of serious	Not assessed	Not assessed	Not assessed	Not assessed

Data (VALiD) Working Group. Public perspectives on consent for the linkage of data to evaluate vaccine safety. Vaccine. 2012 Jun 13;30(28):4167-74.	<i>"we examined consent preferences, trust in the protection of privacy for data linkage, and attitudes towards vaccination in terms of its public health benefit, safety, and effectiveness."</i>		reactions and the effectiveness of vaccines displayed mistrust in the privacy protections used in data linkage and wanted to act as gatekeepers in the use of their children's health information through the implementation of some form of consent				
Cooper DL, Hernandez ND, Rollins L, Akintobi TH, McAllister C. HPV vaccine awareness and the association of trust in cancer information from physicians among males. Vaccine. 2017 May 9;35(20):2661-7.	Trust featured in one of the 2 study aims. <i>"the purpose of this study is to: (1) assess awareness of men about HPV and HPV vaccine by race/ethnicity and (2) examine the association of trust in information from physicians about cancer and even hearing about HPV and HPV vaccine."</i>	Single item measuring trust in HCP: <i>"How much would you trust information about cancer from a doctor?"</i> Measurement allowed four response options, reduced to three during analysis (Not at all to A little/Some/A lot)	Not assessed	Study examines the awareness of HPV. Across race there was a significant difference in trust ($p<0.001$). Hispanics trusted information from their HCP significantly less than White and black Trust not significant in regression model predicting awareness of HPV	Not assessed	Not assessed	Not assessed
Freed GL, Clark SJ, Butchart AT, Singer DC, Davis MM. Sources and perceived credibility of vaccine-safety information for parents. Pediatrics. 2011;127 Suppl(May 2011):S107-12.	Trust primary focus of study. <i>"Objective: To assess what proportion of parents trust vaccine information from different sources and whether different groups of parents vary in their trust of such information"</i>	Questions asked level of parental trust held by parents in various sources of information about vaccines and their dissemination routes. Measurement allowed four response options (A lot/ Some/ Not at all/ Do not use)	26% endorsed 'a lot' of trust in the HCS	76% endorsed 'a lot' of trust in their HCP	23% endorsed 'a lot' of trust in the government	2% endorsed 'a lot' of trust in celebrities 15% endorsed 'a lot' of trust in friends and family	Not assessed
Freimuth VS, Jamison AM, An J, Hancock GR, Crouse S. Determinants of trust in the flu vaccine for African	Trust featured in all for of the study research questions.	three measures of trust were measured using one item each. Abbreviated item wording were given for each measure of trust	African American reported significantly lower trust than White respondents in the following:	African American reported significantly lower trust than White respondents	No association found	Not assessed	African American reported significantly lower trust than White respondents in

<p>Americans and Whites. Soc Sci Med. 2017;193:70–9.</p>	<p><i>“1. Do African Americans and Whites differ in their level of generalized trust, as well as in their levels of trust in the flu vaccine and trust in the vaccine process? 2. What is the differential role of demographics, racial factors, and ideological beliefs in predicting generalized trust, trust in the flu vaccine and trust in the vaccine process across African Americans and Whites? 3. What is the differential role of generalized trust in predicting trust in the flu vaccine and trust in the vaccine process across African Americans and Whites? 4. Controlling for demographics, racial factors, ideological beliefs and generalized trust, what is the differential role of psychosocial variables in predicting trust in the flu vaccine and trust in the vaccine process across African Americans and Whites?”</i></p>	<ol style="list-style-type: none"> 1. Generalized trust <i>Generally speaking, how much do you trust most people</i> 2. Trust in the flu vaccine <i>Overall, how much do you trust the flu vaccine</i> 3. Trust in the vaccine process When it comes to the flu vaccine process, how much do you trust: (1) the world health organization (2) pharmaceutical or drug companies (3) the U.S. Food and Drug Administration (FDA) (4) the Centers for Disease Control and Prevention (CDC) (5) the health professionals who give the flu vaccine. 4. Trust in the government How much do you trust the government when it comes to u vaccines 5. Trust in your doctor How much do you trust your own personal doctor when it comes to u vaccines 6. Trust in WHO, pharmaceutical companies, FDA, CDC When it comes to the flu vaccine process, how much do you trust the [insert part of HCS] 7. Trust in health professionals When it comes to the u vaccine process, how much do you trust the HEALTH PROFESSIONALS WHO GIVE THE FLU VACCINE whether you go to a doctor’s office, a clinic or a pharmacy 8. Trust in beneficence 	<p>Trust in the information from CDC $p<0.001$, $d^{\sim}=0.18$</p> <p>Trust in the WHO $p<0.001$, $d^{\sim}=0.19$</p> <p>Trust in pharmaceutical companies $p<0.01$, $d^{\sim}=0.15$</p> <p>Trust in the FDA $p<0.05$, $d^{\sim}=0.13$</p> <p>Trust in the CDC $p<0.01$, $d^{\sim}=0.16$</p> <p>Trust in health care professionals $p<0.001$, $d^{\sim}=0.42$</p> <p>The beneficence and the competence of the health care system was also rated lower $p<0.001$, $d^{\sim}=0.22$</p>	<p>in Trust in respondents doctor $p<0.001$, $d^{\sim}=0.30$</p>		<p>generalized trust $p<0.001$, $d^{\sim}=0.52$</p>
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		<p>Overall, how much do you trust that the organizations involved in the flu vaccine make their decisions with the public's best interest in mind</p> <p>9. Trust in competence</p> <p>Overall, how much do you trust that all of these organizations do a good job when it comes to the flu vaccine</p>					
<p>Grabenstein JD, Guess HA, Hartzema AG, Koch GG, Konrad TR. Attitudinal factors among adult prescription recipients associated with choice of where to be vaccinated. Journal of clinical epidemiology. 2002 Mar 31;55(3):279-84.</p>	<p>Research question not explicitly mentioned but trust features within main examined relationships.</p> <p><i>"We explored the hypothesis that demographic differences and perceptions of access, convenience, and trust would explain choices between traditional and non-traditional vaccine providers"</i></p>	<p>Item not found. Question related to <i>"trust of people"</i> in reference to the type of vaccination site.</p> <p>Measurement allowed three response options, combined with <i>"Experience"</i> Question for analysis (Trust them more/trust them less/don't know)</p>	<p>Assessment overlaps considerably with trust in HCP</p>	<p>Study examines trust across site of vaccination.</p> <p>Findings indicated participants significantly more likely ($p<.0001$) to trust traditional sites (e.g. Physician's office) than non-traditional sites (e.g. pharmacy)</p>	Not assessed	Not assessed	Not assessed
<p>Moran MB, Frank LB, Chatterjee JS, Murphy ST, Baezconde-Garbanati L. Information scanning and vaccine safety concerns among African American, Mexican American, and non-Hispanic White women. Patient education and counseling. 2016 Jan 31;99(1):147-53.</p>	<p>Trust features within the second aim of the study.</p> <p><i>"A secondary aim of this study was to investigate the relationships between vaccine safety concerns, information scanning, and trust in interpersonal sources of information among three ethnic groups—African American, Mexican American and non-Hispanic White."</i></p>	<p>Trust in various trust subject (listed below) were measured on a single item Likert scale from 1 ("not at all") to 10 ("a great deal") each.</p> <p>Included trust subjects:</p> <ul style="list-style-type: none"> • Respondents mother • Respondents female friends • Respondents female relatives • Respondents health care provider/doctor/nurse's 	Not assessed	<p>HCP were a strongly trusted source of information (averaging 9.18)</p>	Not assessed	<p>Friends Mothers were a strongly trusted source of information (averaging 8.04)</p> <p>Participants reported a moderate level of trust in female relatives (averaging 6.91) and friends (averaging 6.78)</p> <p><i>"Among Mexican Americans, talking to other people for health information was also associated with increased vaccine safety concerns ($R^2 = .078$, $F(9,238) = 2.225$, $p = .021$). Trust in one's</i></p>	Not assessed

						<i>mother for health information was also associated with increased vaccine safety concerns and trust in one's doctor was associated with decreased vaccine safety concerns ($R^2 = .086$, $F(6,239) = 3.759$, $p = .001$)."</i>	
Wada K, Smith DR. Mistrust surrounding vaccination recommendations by the Japanese government: results from a national survey of working-age individuals. BMC public health. 2015 Apr 26;15(1):426.	Trust features within the aim of the study <i>"the current study was undertaken to investigate associations between mistrust for governmental recommendations on vaccination and social background in the working-age population of Japan."</i>	Single item measuring trust in government. <i>"Do you trust the recommendations by the government about Vaccination?"</i> Measurement allowed four response options (1= Yes, certainly, 2= Mostly 3= Not very much, 4= No I don't) Dichotomised for analysis Trust in various trust subject (listed below) were measured on a single item. <i>"Which information source do you trust the most when deciding whether to get vaccinated? (select one only)"</i> <ul style="list-style-type: none"> • Healthcare provider, such as doctors and nurses • Public administration of the national or local government • Family • Friends • TV • Newspapers • The Internet • Books • None of the above 	Not assessed	Not assessed	Respondents who reported mistrust for vaccination were less likely to consider information from the government as their most trusted information source on vaccination, as follows: among men (adjusted Odds Ratio (aOR): 0.33; 95% Confidence Interval (CI): 0.18-0.59), and women (aOR: 0.39; 95% CI: 0.20-0.74)	Respondents who did not trust vaccination recommendations were more likely to consider other information sources as being trustworthy, as follows: the Internet (men, aOR: 1.67; 95% CI: 1.12-2.22; women, aOR: 2.19; 95% CI: 1.58-2.73); books (men, aOR: 2.53; 95% CI: 1.67-3.05; women, aOR: 2.99; 95% CI: 2.19-3.40); newspapers (women, aOR: 1.56; 95% CI: 1.03-2.15), family (women, aOR: 1.60; 95% CI: 1.23-1.99); and friends (men, aOR: 1.96; 95% CI: 1.24-2.60; women, aOR: 1.80; 95% CI: 1.11-2.51).	Not assessed
Won TL, Middleman AB, Auslander BA, Short MB. Trust and a school-located immunization program. Journal of Adolescent Health.	Trust formed the primary focus of study. <i>"Purpose: To determine variables associated with</i>	Five items measuring trust in School Located Immunisation Programs: 1. Sometimes school-located vaccination programs care more about what is	Experimental, intervention study. Trust in School Located Immunisation Program (SLIPs)	Not assessed	Not assessed	Not assessed	Not assessed

2015 May 31;56(5):S33-9. Available from: http://dx.doi.org/10.1016/j.jadohealth.2014.09.018	<i>parental trust in a school-located immunization program (SLIP) and the effect of trust-building interventions on trust and participation in SLIPs."</i>	<p>convenient for them than about the student's immunization needs. *</p> <ol style="list-style-type: none"> School-located vaccination programs are extremely thorough and careful. You completely trust school-located vaccination programs' decisions about which vaccines are best for your child. A school-located vaccination program is totally honest in telling you about all of the different immunization options available for your child All in all, you have complete trust in school-located vaccination programs. <p>*Item reverse coded</p> <p>Measurement was on a 5-point Likert scale (all points labelled: 1=Strongly disagree, 2=Dissagree, 3=Neutral, 4=Agree, 5=Strongly agree)</p> <p>Mean of item responses used for analysis.</p>	<p>Within multivariate regression analysis the following factors significantly predicted trust:</p> <p>Annual household income <£51 000 (B=0.061 p<0.05)</p> <p>Survey language English (B=0.076 p<0.05)</p> <p>Participation in a previous SLIP (B=0.12 p<0.05)</p> <p>Child's health insurance status Medicaid/CHIP (B=0.11 p<0.05)</p> <p>Perceived vaccine importance (B=0.11 p<0.01)</p> <p>Intervention showed slight increase in trust but not significant.</p>				
Wu AC, Wisler-Sher DJ, Griswold K, Colson E, Shapiro ED, Holmboe ES, Benin AL. Postpartum mothers' attitudes, knowledge, and trust regarding vaccination. Maternal and child health journal. 2008 Nov 1;12(6):766-73.	<p>Trust featured in one of the 3 study objectives.</p> <p><i>"The objectives of the study were to assess (1) the frequency that mothers have beliefs that are consistent with the promoters or inhibitors of vaccination, (2) the frequency that mothers do not trust their providers and what determines trust or lack of trust, and (3) maternal knowledge regarding vaccination."</i></p>	<p>Nine items measuring trust in HCP. Six questions were deemed <i>"indicators of lack of trust"</i>, 3 questions were deemed <i>"indicators of positive trust"</i></p> <p>Precise wording of questions was not available however participants were asked to respond to the following statements:</p> <ol style="list-style-type: none"> <i>Afraid doctor will give wrong vaccine</i> <i>Afraid "they" are experimenting when they give vaccines</i> <i>Do not trust information that the doctors give about vaccines</i> 	<p>Study examines <i>"trust regarding vaccines"</i></p> <p>Mothers who were planning to breastfeed (p=0.01), having their first baby (p=0.01) or had an income of <\$40000 but did not receive WIC (p=0.03) were less trusting with regards to vaccines than other mothers.</p>	Not assessed	Not assessed	Not assessed	Not assessed

		<p>4. <i>Pediatrician is only allowed to tell me information about vaccines in a way that makes risks of vaccines seem low</i></p> <p>5. <i>Pediatrician does not have time to talk with me about vaccines</i></p> <p>6. <i>Pediatrician does not want me to ask a lot of questions about vaccines</i></p> <p>7. <i>Comfortable talking to pediatrician about vaccines</i></p> <p>8. <i>Reason to vaccinate is that the pediatrician recommends it</i></p> <p>9. <i>Doctors are supportive of my worries about vaccination</i></p> <p>Measurement was on a 7-point Likert scale (end points: 1=strongly agree, 7=strongly disagree).</p> <p>Items 7,8,9 were reverse coded and a summation gave a trust rating between 7-63. Higher values indicating higher levels of trust</p>					
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Recorded effect of trust on intention to recommend (HCPs)

Ref.	Definition of trust	Aim of study/Research question	Question included to measure type of trust	Trust in HCS	Trust in science	Trust in government
McPhillips HA, Davis RL, Marcuse EK, Taylor JA. The rotavirus vaccine's withdrawal and physicians' trust in vaccine safety mechanisms. Archives of pediatrics & adolescent medicine. 2001 Sep 1;155(9):1051-6.	Trust was not explicitly defined.	<p>Trust mentioned prominently within objective of study.</p> <p><i>“To determine how the withdrawal from the market of the rotavirus vaccine has affected physicians’ trust in vaccine safety mechanism, future adherence to vaccine recommendations, and willingness to use a new rotavirus vaccine.”</i></p>	<p>Single item measuring trust in HCS: <i>“The withdrawal from the market of the rotavirus vaccine has made my patients distrustful of new vaccines”</i></p> <p>Measurement was on a 5-point Likert scale reduced to two points for analysis (“strongly agree/agree” or “neutral/disagree/strongly disagree”)</p>	40% of physicians felt their patients were more concerned about vaccine safety than ever before, but only 30% of physicians felt that the withdrawal of vaccine increased distrust of new vaccines	Not assessed	Not assessed

Raude J, Fressard L, Gautier A, Pulcini C, Peretti-Watel P, Verger P. Opening the 'Vaccine Hesitancy' black box: how trust in institutions affects French GPs' vaccination practices. Expert review of vaccines. 2016 Jul 2;15(7):937-48.	Trust not explicitly defined	Trust formed the primary focus of study. <i>"Our underlying hypothesis was that the influence of trust in institutions on GPs' Vaccine recommendation practices may be mediated to a large extent by three proximal variables: confidence in vaccine (beliefs about their safety), complacency (beliefs about the importance of immunization), and self-efficacy."</i>	Four items measuring trust. <i>Do you trust the following sources to give you reliable information on the benefits and risks of vaccines?</i> <ul style="list-style-type: none"> - <i>The Health Ministry</i> - <i>The Health agencies (e.g. national institute for disease prevention and health education, national drug agency, etc)</i> - <i>Scientific sources (learned societies, scientific journals)</i> - <i>Your specialist colleagues (e.g. in a hospital or vaccination center)</i> Measurement was on a 4-point Likert scale (Do not trust at all / distrust somewhat / trust somewhat / trust completely. Don't know option also available separately.)	Combined trust in HCS, science and government while not having a direct effect on likelihood of recommendation through lower safety concerns ($B=-0.43$ $p<0.001$), lower complacency ($B=-0.65$ $p<0.001$) and higher self-efficacy ($B=0.29$ $p<0.001$)	Trust in science combined with trust in HCS and trust in government	Trust in government combined with trust in HCS and trust in science
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Qualitative findings

Ref.	Aim of the research/ research overview	Trust related main findings
Brownlie J, Howson A. 'Between the demands of truth and government': Health practitioners, trust and immunisation work. Social science & medicine. 2006 Jan 31;62(2):433-43.	No specific aim intended however the study reports a reanalysis of previous related data in which the authors examine <i>"theoretical links between risk, trust</i>	Like patients, HCPs form trust judgements of the HCS through similar means.

	<i>and knowledge in relation to the governance of health”</i>	<p>Perceived trust issues are said to occur between patients and their HCP due to financial incentives given to HCPs for achieving vaccination targets. This issue of financial incentives had an overlapping influence with trust in information. A perception of bias that the information points overwhelmingly towards vaccination.</p> <p>A concern was reported that the HCS official information is perceived as less trustworthy when it is being given out by health visitors</p>
Bunton V, Gilding M. Confidence at the expense of trust: The mass adoption of the Human Papillomavirus vaccine in Australia. <i>Health Sociology Review</i> . 2013 Mar 1;22(1):88-97.	The study investigates women’s knowledge and awareness about cervical cancer diagnostics and how they might be improved. The study coincided with the roll out of the HPV mass vaccination campaign.	<p>The intuitional endorsement of the vaccine added to the perception that the HPV vaccine was necessary and safe.</p> <p>Pharmaceutical proffering due to vaccination campaign indicated a trust issues and the potential for being exposed to misleading or biased information.</p> <p>High levels of trust in other vaccination programs were said to be generalized over to the new campaign for the HPV vaccine.</p>
Harris LM, Chin NP, Fiscella K, Humiston S. Barrier to pneumococcal and influenza vaccinations in Black elderly communities: mistrust. <i>Journal of the National Medical Association</i> . 2006 Oct;98(10):1678.	The study investigates the role of trust of medical institutions in the decision by elderly black Americans to receive pneumococcal and influenza vaccinations.	<p>Mistrust in the HCS and in influenza vaccination was seen as a symptom of long term racial neglect.</p> <p>Historical medical injustices or medical mistakes were seen to negatively impact trust however trust was said to recover when care was good overtime.</p>
Hilton S, Petticrew M, Hunt K. Parents' champions vs. vested interests: who do parents believe about MMR? A qualitative study. <i>BMC Public Health</i> . 2007 Mar 28;7(1):42.	To examine parents’ views on the role the media, politicians and health professionals have played in providing credible evidence about MMR safety	<p>Concerns of who to trust to provide unbiased information were reported.</p> <p>Some parents say HCPs have a vested interest in vaccination due to financial incentives. This in turn violated the trust placed in them.</p> <p>Other parents were also seen as a credible source to trust in with regards to information about vaccination. The argument being that they were more impartial as they were seen to have no “hidden agenda”</p> <p>Previous government performance during the BSC crises was cited by parents alongside the Prime Minister Tony Blair’s refusal to confirm in 2001 whether his son received the MMR vaccine as possible reasons to for low levels of trust. “He may be pushing a programme that he doesn’t believe in” p.5</p>
King C, Leask J. The impact of a vaccine scare on parental views, trust and information needs: a qualitative study in Sydney, Australia. <i>BMC public health</i> . 2017 Jan 23;17(1):106. Available from: http://dx.doi.org/10.1186/s12889-017-4032-2	<i>“This qualitative study aimed to explore the impact of the vaccine suspension on parental knowledge, attitudes, trust, information needs, and intent related to influenza vaccination and broader immunisation programs”</i>	<p>The need for information from a trusted source was reported as an important factor in allaying concerns about vaccination.</p> <p>GPs were acknowledged as a trusted source of information for many. However, obtaining information from GPs was not always see as a practical solution as GPs were not immediately accessible and only consulted if a family member was unwell. Instead, freely accessible, authoritative sources of information were preferred</p> <p>For some parents there was a gap in trust levels that would be hard to overcome with information provision alone</p>

Senier L. "It's Your Most Precious Thing": Worst-Case Thinking, Trust, and Parental Decision Making about Vaccinations. Sociological Inquiry. 2008 May 1;78(2):207-29.	To examine the relationship between risk perception, trust and information.	Interviewees reported concerns about financial incentives as a violation to trustworthiness of HCS. This in turn led to the distrust of probabilistic information offered by the source. Makes distinction between social trust (in the form of "best interests at heart") and confidence, (in the form of role performance) when trusting HCPs Confidence was said to be assessed by checking the advice received against their own common sense or against information from other sources
Quinn S, Jamison A, Musa D, Hilyard K, Freimuth V. Exploring the Continuum of Vaccine Hesitancy Between African American and White Adults: Results of a Qualitative Study. PLoS currents. 2016 Dec 29;8.	1. What is the difference in the degree of vaccine hesitancy between African American and White adults related to seasonal influenza immunization? 2. What impact do cultural, attitudinal and social differences have on vaccine hesitancy? 3. Are the vaccine narratives of both African American and White adults accurately reflected in the Three Cs framework?	

Appendix C: Supplemental materials for chapter 3 systematic review

Articles included in review

Reference number	Author/ Year	Vaccine	Design	Sample	Country (state/city/region)
59	Campbell, Edwards, Letley, Bedford, Ramsay & Yarwood 2017	General childhood	Cross-sectional survey	N= 1792 parents of whom 1130 had children aged 0-2 years and 999 had children aged 3-4 years.	UK
167	Agree, King, Castro, Wiley & Lg 2015	Seasonal influenza	Experimental	N=346 men and women aged 35 years and older, diverse racial/ethnic background.	USA (Maryland)
177	Baldwin, Bruce, & Tiro 2011	HPV	Cross-sectional survey	N=256 mothers of unvaccinated girls (49% Black, 29% Hispanic and 18% White).	USA (Dallas and Texas)
178	Benin, Wisler-Scher, Colson, Shapiro & Holmboe 2006	General childhood	Qualitative, open-ended interviews at two time points	N=33 mothers 1 to 3 days postpartum with a follow up interview at 3 to 3 months. N=25 who intended to have their infants vaccinated and N=8 who did not intend or intended to delay/select vaccinations.	USA (Connecticut)
46	Boyd & Gazmararian 2013	H1N1 influenza	Qualitative, focus group (x6) and semi-structured interviews	N=66 staff members of two women, infants and children clinics (one urban and one rural).	USA (Georgia)
179	Brunson 2013	General childhood	Cross-sectional survey	N=196 first time parents with children aged ≤18 month.	USA (Washington state)
180	Clarke & McComas 2012	Seasonal influenza	Cross-sectional survey	N=226 physicians and nurses from a large urban hospital.	USA (New York state)
181	Downs, de Bruin & Fischhoff 2008	General childhood	Qualitative, mental models interviews	N=30 parents of a child between 18 and 23 months of age.	USA (Missouri, Pennsylvania and Oregon)
182	Getman, Helmi, Roberts, Yansane, Cutler	General childhood	Analysis of media monitoring data (USA data only)	Reports the clustering of communities based on vaccine sentiment.	USA

	& Seymour 2017				
183	Hodge, Line-itty & Ellenwood 2011	HPV	Qualitative, focus groups (x8)	N=53 American Indian students from four universities based in either California or Arizona.	USA (California and Arizona)
157	Hughes, Cates, Liddon, Smith, Gottlieb & Brewer 2009	HPV	Cross-sectional survey	N=889 caregivers of adolescent girls between the ages of 10 and 18.	USA (North Carolina)
158	Jones, Omer, Bednarczyk, Halsey, Moulton, Salmon 2012	General childhood	Cross-sectional survey (2003 data)	N=1367 parents of children, 277 of which had vaccination exemptions, from 1000 schools.	USA (Colorado, Massachusetts, Missouri and Washington state)
159	Jung, Lin & Viswanath 2013	H1N1 influenza	Cross-sectional survey	N=639 parents with at least one child less than 18 years of age.	USA
160	Kalichman & Kegler 2015	H1N1 influenza and HPV	Analysis of Google Incite data	Google Incite for Search data from Jan 1 – Dec 31 2009, within the USA.	USA
161	Kim & Real 2016	Seasonal influenza	Cross-sectional survey	N=307 HCPs from three hospitals.	USA (Kentucky)
106	Manika, Ball, Stout & Stout 2014	HPV	Cross-sectional survey	N=117 women between the ages of 18 and 26 attending a large university.	USA
162	Mayne et al 2012	HPV	Cross-sectional survey	N=162 parents of adolescent girls recruited within hospitals.	USA (Philadelphia and Wisconsin)
163	McRee, Reiter & Brewer 2012	HPV	Cross-sectional survey	N=773 parents with daughters and N=115 parents with sons aged 10 to 18 years of age.	USA (North Carolina)
164	McRee, Gottlieb, Reiter, Dittus, Tucker Halpern & Brewer 2012	HPV	Cross-sectional survey	N=900 mothers of girls between the ages of 11 and 14.	USA

165	Sobo, Huhn, Sannwald & Thurman 2016	General childhood	Qualitative semi-structured interview. Content analysis	N= 53 parents of at least one child of kindergarten age or younger.	USA (California)
166	Stevens, Caughy, Lee, Wendy, & Tiro 2013	HPV	Cross-sectional survey	N=288 Hispanic mothers of females aged between 8 and 22.	USA (Dallas and Texas)
168	Weiner, Fisher, Nowak, Basket & Gellin 2015	General childhood	Cross-sectional survey	N=200 first time mothers during their second trimester of pregnancy.	USA
169	Yom-Tov, Fernandez-Luque & Luque 2014	MMR	Analysis of results from various search engine search terms	All search terms related to the MMR vaccine made by users in the USA between Oct 2012 and Mar 2013. 252,526 queries from approximately 115,714 users.	USA
170	Ellingson & Chamberlain 2018	General maternal	Cross-sectional survey	N=408 obstetric patients at four prenatal clinics.	USA (Georgia)
171	McKeever et al 2016	General childhood	Cross-sectional survey	N=455 mothers with young children.	USA
172	Wang, Baras & Bутtenheim 2015	General childhood	Qualitative, semi-structured interviews. Modified Grounded Theory	N=23 high socioeconomic status parents who had at least one child aged 18 months to 6 years.	USA (Philadelphia & Pennsylvania)
173	Wheeler & Bутtenheim 2013	General childhood	cohort	The authors draw on data about an initial vaccine counselling session from 237 unique medical records over a two-year period. The study took place at a private paediatric practice.	USA (Pennsylvania)
174	Hopfer & Clippard 2011	HPV	Qualitative, semi-structured interviews	N=38 college women aged between 18 and 26 (N=36) and college health clinicians(N=2) from a large university.	USA (Pennsylvania)
175	Kowal, Jardine & Bubela 2015	Vaccination in general	Qualitative semi-structured interviews. Content analysis	N=23 Bhutanese, South Asian and Chinese immigrant mothers with at least one child under eight years old based in Alberta Canada	Canada (Alberta)

176	Greenberg, Dube & Driedger 2017	General childhood	Cross-sectional survey	N = 1000 parents of children aged 5 and younger based in Canada	Canada
184	Betsch & Wicker 2012	Seasonal influenza	Cross-sectional survey	N=310 medical students at Frankfurt University Hospital.	Germany (Frankfurt)
185	Bianco et al 2013	General childhood	Cross-sectional survey	N=1039 adults selected among parents of public school students.	Italy (Catanzaro region)
186	Bults, Beaujean, Richardus, Steenbergen & Voeten 2011	H1N1 influenza	Cross-sectional survey	N=3,127 (1227 acceptors, 1900 refusers) adults.	The Netherlands
187	Fadda, Galimberti, Carraro & Schulz 2016	MMR	Qualitative, focus groups (x6)	N=28 parents (24 mothers and 4 fathers) of children whom the MMR vaccination decision was still pending. From 11 vaccination centres.	Italy (Trento province)
188	Harmsen, Doorman, Mollema, Ruiter, Kok & Melker 2013	General Childhood	Cross-sectional survey	N= 592 parents with at last one child aged between 0-4 years.	The Netherlands
189	Penta & Baban 2014	HPV	Qualitative/Quantitate, content and thematic analysis	Analysis of conversations on N=20 online discussion forums related to the HPV vaccine.	Romania
14	Poltorak, Leach, Fairhead & Cassell 2005	MMR	Qualitative, semi-structured interviews	N=48 mothers of young children.	UK (Brighton)
48	Walter, Böhmer, Reiter, Krause, & Wichmann 2012	H1N1 influenza	A series of 13 cross-section surveys from Nov 16 th 2009 to April 14 th 2010	N=13,010 German-speaking individuals over the age of 14.	Germany
190	Ward et al 2017	HPV	Qualitative, semi-structured interviews.	N=19 mothers of girls between 11-14 years of age.	France

191	Orr, Baram-Tsabari & Landsman 2016	Polio	Qualitative/Quantitate, content and thematic analysis	Analysis of conversations on a Facebook group related to the polio vaccine.	Israel
192	Sagy, Novack, Gdalevich, Greenberg 2018	Polio	Time trend analysis assessing the association between prominent media reports and vaccines uptake	Association between daily estimated value of advertising reports (news related to polio) and the immunisation of N=138 799 children under the age of 10.	Israel
193	Kim & Jung 2017	Seasonal influenza	Cross-sectional survey	N=1367 adults.	South Korea
194	Lee & Kim 2015	General childhood	Cross-sectional survey	N=1004 mothers with a children younger than 12 years of age.	South Korea
195	Kim 2018	HPV	Cross-sectional survey	N=323 undergraduate students.	South Korea
196	Mus, Krijckap-kaspers, Mcguire, Deckx, & Driel 2017	General childhood	Mixed, Content analysis	Analysis of N=1,342 calls made to a pharmacist-operated medicines call centre.	Australia
197	Nicholson & Leask 2011	MMR	Qualitative/Quantitate, content and thematic analysis	Analysis of online discussion held following an Australian national TV screening of a documentary about the MMR vaccine.	Australia
198	King, Chow, Wiley & Leask 2018	H1N1 influenza	Cross-sectional survey	N=431 parents of children aged 6 months to 5 years of ages.	Australia (Sydney)
199	Cheung, Lee & Lee 2017	Seasonal influenza	Cross-sectional survey	N=1199 nurses practising.	China (Hong Kong)
200	Bragazzi et al 2017	Vaccination in general	Analysis of Google Trends data	Vaccine related google trends data from 2004-2017	N/A
201	Warren & Wen 2016	MMR	Analysis of Google Trends data	Reports two case studies of social media being used for contact tracing	N/A
202	Dunn, Leask, Zhou, Mandl & Coiera 2015	HPV	Analysis of twitter comments related to HOV	Reports the clustering of communities based on vaccine sentiment.	N/A

203	Schmidt, Zollo, Scala, Betsch & Quattrocioni 2018	Vaccination in general	Qualitative/Quantitative, content and thematic analysis	Analysis of conversations on a Facebook group related to vaccination attitudes in general	N/A

Supplemental materials 2: Differences in channel/source definition with in study

Channels	Studies	Range of channel options reported in studies
HCS	Betsch & Wicker 2012 Brunson 2013 Campbell, Edwards, Letley, Bedford, Ramsay & Yarwood 2017 Hodge, Line-itty & Ellenwood 2011 Jones, Omer, Bednarczyk, Halsey, Moulton, Salmon 2012 Kim & Real 2016 King, Chow, Wiley & Leask 2018 Walter, Böhmer, Reiter, Krause, & Wichmann 2012	<ul style="list-style-type: none"> • Clinic • Government • Government resources • Handouts, public health mailings • Information materials from official authorities • Local or state health department • Pharmacies • Professional organizations such as doctors nurse association
HCP	Baldwin, Bruce, & Tiro 2011 Betsch & Wicker 2012 Bianco et al 2013 Campbell, Edwards, Letley, Bedford, Ramsay & Yarwood 2017 Greenberg, Dube & Driedger 2017 Harmsen, Doorman, Mollema, Ruiter, Kok & Melker 2013 Hodge, Line-itty & Ellenwood 2011 Hughes, Cates, Liddon, Smith, Gottlieb & Brewer 2009 Jones, Omer, Bednarczyk, Halsey, Moulton, Salmon 2012 Jung, Lin & Viswanath 2013 Kim 2018 King, Chow, Wiley & Leask 2018 Manika, Ball, Stout & Stout 2014 Walter, Böhmer, Reiter, Krause, & Wichmann 2012 Weiner, Fisher, Nowak, Basket & Gellin 2015 Wheeler & Buttenheim 2013	<ul style="list-style-type: none"> • Doctor • GP • Health care professional • Health care provider • Health care providers advice • Medical professional • My doctor • Nurse • Physician • Printed materials from health care provider • Public health officials • Talked with doctor • Pharmacist
Print media	Betsch & Wicker 2012 Bianco et al 2013	<ul style="list-style-type: none"> • Books

	<p>Brunson 2013 Campbell, Edwards, Letley, Bedford, Ramsay & Yarwood 2017 Greenberg, Dube & Driedger 2017 Hughes, Cates, Liddon, Smith, Gottlieb & Brewer 2009 Jones, Omer, Bednarczyk, Halsey, Moulton, Salmon 2012 Kim & Real 2016 Kim 2018 Manika, Ball, Stout & Stout 2014 Walter, Böhmer, Reiter, Krause, & Wichmann 2012 Wheeler & Buttenheim 2013</p>	<ul style="list-style-type: none"> • Libraries • Local newspaper • Media • News media • Newspapers and magazines • Print source • Reference books
Broadcast media	<p>Betsch & Wicker 2012 Bianco et al 2013 Campbell, Edwards, Letley, Bedford, Ramsay & Yarwood 2017 Greenberg, Dube & Driedger 2017 Hodge, Line-itty & Ellenwood 2011 Jung, Lin & Viswanath 2013 Kim & Real 2016 Kim 2018 Manika, Ball, Stout & Stout 2014 Walter, Böhmer, Reiter, Krause, & Wichmann 2012 Weiner, Fisher, Nowak, Basket & Gellin 2015</p>	<ul style="list-style-type: none"> • Cable TV • Commercials • Local TV • Mass media • Media • National TV • News media • Non-english TV • Radio • Traditional media • TV
Academic media	<p>Betsch & Wicker 2012 Bianco et al 2013 Brunson 2013 Greenberg, Dube & Driedger 2017</p>	<ul style="list-style-type: none"> • Academics • Courses and lectures • Scientific journals
Internet	<p>Betsch & Wicker 2012 Bianco et al 2013 Brunson 2013 Ellingson & Chamberlain 2018 Harmsen, Doorman, Mollema, Ruiter, Kok & Melker 2013 Hughes, Cates, Liddon, Smith, Gottlieb & Brewer 2009 Kim & Real 2016 Kim 2018 Manika, Ball, Stout & Stout 2014 Weiner, Fisher, Nowak, Basket & Gellin 2015 Wheeler & Buttenheim 2013</p>	<ul style="list-style-type: none"> • Apps (for smartphone or tablets) • Internet • Internet health site • Internet search engines • Internet social media • Parenting blogs • Pregnancy website • Social media
Interpersonal (not own HCP)	<p>Baldwin, Bruce, & Tiro 2011 Betsch & Wicker 2012</p>	<ul style="list-style-type: none"> • Colleagues • Family

	<p>Bianco et al 2013 Ellingson & Chamberlain 2018 Greenberg, Dube & Driedger 2017 Harmsen, Doorman, Mollema, Ruiters, Kok & Melker 2013 Hodge, Line-itty & Ellenwood 2011 Jung, Lin & Viswanath 2013 Kim & Real 2016 Kim 2018 Manika, Ball, Stout & Stout 2014 Weiner, Fisher, Nowak, Basket & Gellin 2015 Wheeler & Buttenheim 2013</p>	<ul style="list-style-type: none"> • Friends • Parent professional background • Relatives • Siblings • Talked with others • Tribal community
Complementary and Alternative Medicine providers	<p>Jones, Omer, Bednarczyk, Halsey, Moulton, Salmon 2012 King, Chow, Wiley & Leask 2018 Weiner, Fisher, Nowak, Basket & Gellin 2015</p>	<ul style="list-style-type: none"> • Alternative healthcare providers • Anti-vaccination groups • Complementary healthcare professional • Natural therapist
Other organisations where health is not their primary function	<p>Hodge, Line-itty & Ellenwood 2011 King, Chow, Wiley & Leask 2018</p>	<ul style="list-style-type: none"> • Childcare centre • Religious leaders and organisations • School
Celebrities	<p>King, Chow, Wiley & Leask 2018 Greenberg, Dube & Driedger 2017</p>	<ul style="list-style-type: none"> • Celebrities • Celebrity physicians

Appendix D: Exploratory factor analysis of the Psychosocial Determinants of Vaccine Information Seeking Behaviour Scale

In order to validate the Psychosocial Determinates of Vaccine Information Seeking Behaviour Scale an exploratory factor analysis using principle components analysis with a varimax rotation was conducted.

Scale Development

An exploratory factor analysis using principal component extraction method was conducted for the Psychosocial Determinants of Vaccine Information Seeking Behaviour Scale. This analysis suggests a four factor model. A total of 366 participants fully completed the Psychosocial Determinants of Vaccine Information Seeking Behaviour Scale. The Kaiser-Meyer-Olin (KMO) measure of sampling adequacy was 0.860 and the Bartlett's test of sphericity was significant, $\chi^2(120) = 2548.7, p < .001$ indicating that the data were suitable for exploratory factor analysis. Principle components analysis extracted 4 components with eigenvalues >1.0 which in total explained 65.1% of the variance. A varimax rotation was then applied in order to simplify the structure of each factor. Table 1 shows the loading of each of the 16 items on four factors suggested by the analysis. Those items with loadings <0.7 were later excluded from the scale in further analyses. From the factor analysis two items were discarded due to low loading on to factor one (Q4 and Q5) and two items were shifted out of the proposed factor one so as to form the factor of Descriptive Norms. Further analyses utilised all four of these sub variables. When used to predict responses to overall intentions to search for information about vaccination (Q17) the four factors predicted 57.7% of the variance, $F(4, 361) = 125.3, p < .001$.

Table 1: Principle component analysis for the Psychosocial Determinates of Vaccine Information Seeking Scale

	<i>Mean</i>	<i>SD</i>	<i>Loading</i>
Factor 1: Attitudes and beliefs towards vaccine information seeking behaviour			
<i>Looking for additional information about vaccination is important</i>	5.18	1.69	.754
<i>Looking for additional information about vaccination is wise</i>	5.33	1.60	.765
<i>Looking for additional information about vaccination increases my knowledge</i>	5.86	1.40	.758
<i>Looking for additional information about vaccination makes it easier to decide whether to vaccinate*</i>	4.94	1.96	.631
<i>By looking for additional information about vaccination makes it easier to talk with other people about vaccination*</i>	5.27	1.62	.540
Factor 2: Descriptive normative beliefs towards vaccine information seeking behaviour			
<i>Talking about the vaccinations with other people is important</i>	4.90	1.75	.852
<i>Talking about the vaccinations with other people is wise</i>	5.04	1.68	.854
Factor 3: Injunctive normative beliefs towards vaccine information seeking behaviour			
<i>My friends think I should look for additional information when making a vaccination decision</i>	3.45	1.79	.772

<i>My family think I should look for additional information when making a vaccination decision</i>	3.39	1.97	.771
<i>My general practitioner thinks I should look for additional information when making a vaccination decision</i>	3.07	1.69	.715
Factor 4: Perceived behaviour control towards vaccine information seeking behaviour			
<i>I have confidence that I am able to look for additional information about vaccinations</i>	6.10	1.29	.721
<i>I have enough skills to look for additional information about vaccinations</i>	6.21	1.18	.703
<i>I am confident that I can assess the reliability of information about vaccinations</i>	5.56	1.54	.806
<i>After looking for additional information I am likely to be confident in my decision</i>	5.78	1.43	.723
<i>I have enough skills to assess the reliability of information about vaccinations</i>	5.84	1.36	.786
<i>After reading about the pros and cons of vaccination, I am likely to be confident in any final decision that I make</i>	5.95	1.34	.777
Intention to seek additional information about vaccination			
<i>I expect that I will search for additional information about vaccinations in the future**</i>	5.01	1.94	N/A

*Item removed from scale for further use due to low factor loading

** Predictor/scale validity variable.

Appendix E: Questionnaire 1

Your experiences related to health care and the whooping cough vaccination given during pregnancy

PRIMARY INVESTIGATOR: Mr Richard Clarke Bsc, Msc

ADDITIONAL INVESTIGATORS: Dr Pauline Paterson, Dr Miroslav Sirota

INVITATION

You are being asked to take part in a research study related to your experiences during a recent pregnancy. You are eligible to take part in this research if you have given birth anytime within 6 months prior to receiving this questionnaire, you have been living in England or Wales during the majority of your pregnancy and you are fluent in English.

This project has received ethical approval [LSHTM ethics REF: 11847]. It forms part of a set of studies being conducted for a PhD research project based at The London School of Hygiene & Tropical Medicine.

WHAT WILL HAPPEN

In this study, you will complete a survey about your experiences and opinions of the care you received during pregnancy. You will be asked some general as well as specific questions surrounding your experience with the whooping cough vaccination that may or may not have been offered to you during your pregnancy.

TIME COMMITMENT

The survey will typically take 15-20 minutes to complete. We suggest that you find a more quiet time during the day where you are less likely to be disturbed (we realise this may not be easy with a new-

born baby). If you do need to take a break for any reason your place in the survey will be saved and you will be able to return and continue any time within 24 hours.

COMPENSATION

To compensate you for your time and effort at the end of the survey you have the opportunity to be entered into a prize draw to win one of three gift vouchers (2 x £50, 1 x £100) of your choice (Mothercare or Amazon).

If you would like to participate in the survey please continue to the next page where you will be informed of details relating to confidentiality and anonymity related to the responses that you give during the course of completing this questionnaire.

Participant consent

PARTICIPANTS' RIGHTS

Participation in this research study is completely voluntary. Even after you agree to participate and begin the study, you are still free to withdraw at any time and without having to give a reason. Only the data from respondents that complete the full survey will be used in later analysis.

If, for any reason, you would like to withdraw your data from the study after you have completed the questionnaire you can contact the primary investigator (Richard.clarke@lshtm.ac.uk) anytime within two weeks of completion and the data will be removed from any analyses.

DATA STORAGE AND FUTURE USE

The data we collect for research purposes shall not contain any personal information about you, other than your age, ethnicity and the first part of your post code. No one will link the data you provide to the identifying information you supply (e.g., your name or e-mail address).

All data will be stored securely at The London School of Hygiene & Tropical Medicine. This data will be published in aggregate and may be shared publically with the intent to aid related research and

public health communication. In the case of this anonymity will be assured through the removal of potentially identifiable information.

RISKS/DISCOMFORT

There are no known risks for you in taking part in this study however a few of the questions may be of a personal nature. If you do experience any stress or discomfort as a result of the issues raised here it is recommended that you discuss these feelings with a close friend or relative and if feelings of distress continue to contact your GP or local counselling service

FOR FURTHER INFORMATION

If you are affected by any of the issues raised by this questionnaire or have any additional questions/comments feel free to contact me (Richard Clarke) at any time and I will be happy to answer your questions or direct you to an appropriate expert. You can reach me on:
Richard.clarke@lshtm.ac.uk

This contact e-mail (and those of the other investigators) and a full explanation of the reason for this study are included at the end of the survey.



In order to continue please read and consent to the following:

	Tick to consent
I have read and understood the above information and have no further questions regarding my participation in this study:	<input type="checkbox"/>
I understand that my participation is voluntary, and I am free to withdraw from the survey at any time without any obligation to explain my reasons for doing so:	<input type="checkbox"/>
I agree to the data I provide being analyzed and published anonymously:	<input type="checkbox"/>

End of Block: Consent page

Start of Block: Inclusion/exclusion

Thank you for agreeing to participate in this research. First we would like to ask a few general questions about you to find out whether you are eligible to take part.

	Yes	No
Have you given birth during the last 6 months as of receiving this survey?	<input type="radio"/>	<input type="radio"/>
Did you spend the majority of your pregnancy in England or Wales?	<input type="radio"/>	<input type="radio"/>
Would you describe your level of English as fluent?	<input type="radio"/>	<input type="radio"/>

End of Block: Inclusion/exclusion

Start of Block: Block 1



Age in Years



First part of your postcode (e.g. CM9 or NW10)

Which ethnic group do you belong to

- ☐ White:- British
- ☐ White:- Irish
- ☐ White:- Other white background
- ☐ Mixed:- White and Black Caribbean
- ☐ Mixed:- White and Black African
- ☐ Mixed:- White and Asian
- ☐ Mixed:- Other mixed background
- ☐ Asian or Asian British:- Indian
- ☐ Asian or Asian British:- Pakistani
- ☐ Asian or Asian British:- Bangladeshi
- ☐ Asian or Asian British:- Other Asian background
- ☐ Chinese
- ☐ Other ethnic group not represented by these options
- ☐ Do not wish to say



How many pregnancies have you had that have entered or passed the 3rd trimester (week 29 – 40)?

End of Block: Block 1

Start of Block: Block 2

Thank you, now that the basic information is out of the way the following questions on the next two pages address how you feel about the health care system and the individuals you have had contact with during the course of your pregnancy.

The following statements refer to your relationship with the Health Care System in general. By **Health Care System** we mean: hospitals, GP practices, community clinics, and laboratories as well as organizations involved in health, such as insurance companies and pharmaceutical companies. We are **not including** people such as doctors, nurses, specialists, x-ray technicians, medicines, or office staff. We are just talking about the organizations that are a part of your general health care.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
The Health Care System does its best to make patients' health better.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Health Care System covers up its mistakes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patients receive high quality medical care from the Health Care System.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Health Care System makes too many mistakes.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Health Care System puts making money above patients' needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Health Care System gives excellent medical care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patients get the same medical treatment from the Health Care System, no matter what the patients' race or ethnicity.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Health Care System lies to make money.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Health Care System experiments on patients without them knowing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Block 2

Start of Block: Block 3

Think about your **primary health care professional (midwife, GP, obstetrician, nurse)** during your last pregnancy (If you had multiple health care professionals during this time think about the one that you saw most often between week 10 and week 38 of your pregnancy). For the

following statements select your level of agreement based on your feelings towards this individual.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
Your health care professional did whatever it took to get you all the care you needed during your pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sometimes your health care professional cared more about what was convenient for [him or her] than about your medical needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your health care professional's medical skills were not as good as they should have been	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your health care professional was extremely thorough and careful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
You completely trusted your health care professional's decisions about which medical treatments were best for you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your health care professional was totally honest in telling you about all of the different options available to you during your pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your health care professional only thought about what was best for you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sometimes your health care professional did not pay full attention to what you were trying to tell [him or her]	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

You had no worries
about putting your life
in your health care
professional's hands

All in all, you had
complete trust in your
health care
professional

☐ ☐ ☐ ☐ ☐

☐ ☐ ☐ ☐ ☐

End of Block: Block 3

Start of Block: Block 4

You're doing great! This next set of questions is slightly different. It is used to find out how you deal with events that trouble you in your day-to-day life.

First, we'd like you to take a few moments and think about an event or situation that has been very stressful for you during the last month. By stressful we mean a situation that was troubling you, either because it made you feel bad or because it took effort to deal with it. It might have been with your family, with your school or university, with your job, or with your friends.

In the space below, please describe this stressful event. Please describe what happened and include details such as where it happened, who was involved (not including specific names), what made it important to you, and what you did. The situation could be one that is going on right now or one that has already happened (not necessarily linked to pregnancy).

Don't worry about writing an essay. Just put down the things that come to you. This is to check that you've got a stressful event in mind and it's an opportunity for you to get the event straight in your head before answering the following questions.

As you read through the following items please answer them based on how you handled your event.
There are no right or wrong answers.

Please read each item below and determine the extent to which you used it in handling your chosen event:

	Not at all	A little	Somewhat	Much	Very much
I worked on solving the problems in the situation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I looked for the silver lining, so to speak; I tried to look on the bright side of things.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I let out my feelings to reduce the stress.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found somebody who was a good listener.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I went along as if nothing were happening.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I hoped a miracle would happen.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I realized that I was personally responsible for my difficulties and really lectured myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I spent more time alone.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I made a plan of action and followed it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I looked at things in a different light and tried to make the best of what was available.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Not at all	A little	Somewhat	Much	Very much
I let my feelings out somehow.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I talked to someone about how I was feeling.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I tried to forget the whole thing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I wished that the situation would go away or somehow be over with.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I blamed myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I avoided my family and friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I tackled the problem head on.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I asked myself what was really important, and discovered that things weren't so bad after all.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I let my emotions out.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I talked to someone that I was very close to.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I didn't let it get to me; I refused to think about it too much.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



	Not at all	A little	Somewhat	Much	Very much
I wished that the situation had never started.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I criticized myself for what happened.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I avoided being with people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I knew what had to be done, so I doubled my efforts and tried harder to make things work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I convinced myself that things aren't quite as bad as they seem.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I got in touch with my feelings and just let them go.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I asked a friend or relative I respect for advice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I avoided thinking or doing anything about the situation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I hoped that if I waited long enough, things would turn out ok.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Since what happened was my fault I was really hard on myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I spent some time by myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Block 4

Start of Block: Block 5

The following questions are intended to assess your personal opinion about seeking and considering additional information when making a decision about vaccination. 'Additional information' here

could refer to information other than that given or gained from a conversation with your primary health care professional (e.g. news articles, websites, conversation with other health care professional, friends or a family members or anything else that would assist you in a decision).

Looking for additional information about vaccination is important

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

Looking for additional information about vaccination is wise

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

Looking for additional information about vaccination increases my knowledge

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

Looking for additional information about vaccination makes it easier to decide whether to vaccinate

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

Looking for additional information about vaccination makes it easier to talk with other people about vaccination

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

Talking about vaccinations with other people is important

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

Talking about vaccinations with other people is wise

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

My friends think I should look for additional information when making a vaccination decision

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

My family think I should look for additional information when making a vaccination decision

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

My general practitioner thinks I should look for additional information when making a vaccination decision

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

I have confidence that I am able to look for additional information about vaccinations

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

I have enough skills to look for additional information about vaccinations

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

I am confident that I can assess the reliability of information about vaccinations

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

I have enough skills to assess the reliability of information about vaccinations

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

After looking for additional information I am likely to be confident in my decision

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

After reading about the pros and cons of vaccination, I am likely to be confident in any final decision that I make

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

I expect that I will search for additional information about vaccinations in the future

	1	2	3	4	5	6	7	
Totally disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Totally agree

End of Block: Block 5

Start of Block: Block 6

The following questions refer to the whooping cough (also known as pertussis) vaccine that is often given to pregnant women between week 20 and week 36 of their pregnancy.

	Yes	No
During your last pregnancy were you aware (or at least partially aware) that it is currently recommended that all pregnant women receive the whooping cough vaccine during pregnancy?	<input type="radio"/>	<input type="radio"/>

	Yes	No	Cannot remember
Were you encouraged to vaccinate against whooping cough by a health care professional?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Display This Question:

If the above two questions = Yes

Did you receive the whooping cough vaccination during your last pregnancy?

- ☐ Yes
- ☐ No
- ☐ Don't know

Display This Question:

If the above question = Yes

*

Approximately how many weeks pregnant were you when you had the whooping cough vaccination?

End of Block: Block 6

Start of Block: Block 7

In general, I am...

- ☐ Absolutely against vaccination during pregnancy
 - ☐ Strongly against vaccination during pregnancy
 - ☐ Somewhat against vaccination during pregnancy
 - ☐ Neutral regarding vaccination during pregnancy
 - ☐ Somewhat in favour of vaccination during pregnancy
 - ☐ Strongly in favour of vaccination during pregnancy
 - ☐ Absolutely in favour of vaccination during pregnancy
-

The benefits of **vaccinating against whooping cough** during pregnancy outweigh the risks

- ☐ Strongly disagree
 - ☐ Disagree
 - ☐ Neither agree or disagree
 - ☐ Agree
 - ☐ Strongly Agree
-

Whooping cough (as a disease) is common in my area among babies and children.

- ☐ Strongly disagree
 - ☐ Disagree
 - ☐ Neither agree or disagree
 - ☐ Agree
 - ☐ Strongly Agree
-

Whooping cough (as a disease) is common in my area among adults.

- ☐ Strongly disagree
 - ☐ Disagree
 - ☐ Neither agree or disagree
 - ☐ Agree
 - ☐ Strongly Agree
-

Whooping cough (as a disease) can cause severe health issues

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
For an unborn baby...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
For a baby or child...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
For a pregnant women...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
For an adult...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

When given during pregnancy, side effects caused by **the whooping cough vaccine** are likely to cause severe health issues for the pregnant women.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree or disagree
- ☐ Agree
- ☐ Strongly Agree

When given during pregnancy, side effects caused by **the whooping cough vaccine** are likely to cause severe health issues for the unborn baby.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree or disagree
- ☐ Agree
- ☐ Strongly Agree

Side effects from **the whooping cough vaccine** during pregnancy are likely

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
For an unborn baby...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
For a pregnant woman...	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Block 7

Start of Block: Block 8

Next are a range of single questions about your experience with the whooping cough vaccine during your pregnancy

When did you become aware that the whooping cough vaccine is recommended for pregnant women?

- ☐ Before last pregnancy
- ☐ During last pregnancy
- ☐ Cannot remember

Display This Question:

If answer = During last pregnancy

Approximately, what week of pregnancy during last pregnancy.

How did you first become aware about the whooping cough vaccination given during pregnancy?

Tick one

- ☐ Received a leaflet with an antenatal clinic appointment letter or at antenatal clinic
- ☐ During a meeting with a midwife
- ☐ During a meeting with an obstetrician
- ☐ During a meeting with a GP
- ☐ During a meeting with a health visitor
- ☐ During a meeting with a pharmacist
- ☐ During a meeting with a nurse
- ☐ During a meeting with a consultant
- ☐ Public Health Campaign
- ☐ Media (TV, Newspaper)
- ☐ Friend or family member
- ☐ Do not remember
- ☐ Other

Display This Question:

If answer = Other

If other, please state

The following is a list of different health care professionals. Out of the health care professionals you saw during your pregnancy which (if any) gave you the most encouragement to receive the whooping cough vaccine?

- ☐ Midwives
- ☐ Obstetrician
- ☐ GP
- ☐ Health visitor
- ☐ Pharmacist
- ☐ Nurse
- ☐ Consultant
- ☐ Other health care professional
- ☐ None of above

Display This Question:

If answer = Other

If other, please state

Display This Question:

If != None of above

From here on the phrase 'health care professional' will refer to the individual which gave you the most encouragement to receive the whooping cough vaccine.

How strongly did your health care professional recommend that you get the whooping cough vaccine during your pregnancy?

	1	2	3	4	5	6	7	
Health care professional recommended it in passing but appeared to give little importance to it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Health care professional strongly recommended the vaccine and appeared to give great importance to it

During a conversation with your health care professional do you remember being given any of the following literature? Tick all that apply

- ☐ Short flyer titled 'Whooping cough and pregnancy: What you need to know and do to help protect your baby'
- ☐ 6 page (A5) leaflet titled 'Whooping cough and pregnancy: Your questions answered on how to help and protect your baby'
- ☐ 12 page (A4) factsheet titled 'Pertussis (whooping cough) immunisation for pregnant women'
- ☐ 16 page (A5 folded) leaflet titled 'Pregnant? There are many ways to help protect you and your baby'
- ☐ Literature other than above
- ☐ One of these but cannot remember which one
- ☐ Cannot remember
- ☐ None of the above

Skip To: End of Block If During a conversation with your health care professional do you remember being given any of the f... = Cannot remember

Skip To: End of Block If During a conversation with your health care professional do you remember being given any of the f... = None of the above

How closely did you read this literature?

- ☐ Did not read the literature
 - ☐ Read the literature briefly
 - ☐ Read the literature fairly closely
 - ☐ Read the literature thoroughly
-

Display This Question:

If During a conversation with your health care professional do you remember being given any of the f... = Short flyer titled 'Whooping cough and pregnancy: What you need to know and do to help protect your baby'

Or During a conversation with your health care professional do you remember being given any of the f... = 6 page (A5) leaflet titled 'Whooping cough and pregnancy: Your questions answered on how to help and protect your baby'

Or During a conversation with your health care professional do you remember being given any of the f... = 12 page (A4) factsheet titled 'Pertussis (whooping cough) immunisation for pregnant women'

Or During a conversation with your health care professional do you remember being given any of the f... = 16 page (A5 folded) leaflet titled 'Pregnant? There are many ways to help protect you and your baby'

Or During a conversation with your health care professional do you remember being given any of the f... = One of these but cannot remember which one

Or During a conversation with your health care professional do you remember being given any of the f... = Literature other than above

Do you feel this information influenced your decision?

- ☐ Yes greatly influenced
 - ☐ Yes slightly influenced
 - ☐ No influence
-

Display This Question:

If Do you feel this information influenced your decision? = Yes greatly influenced

Or Do you feel this information influenced your decision? = Yes slightly influenced

☐ Towards vaccination

☐ Away from vaccination

How satisfied were you with the **amount** of information given to you by your health care professional(s)?

	1	2	3	4	5	6	7	
Highly dissatisfied with the amount of information given	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Highly satisfied with the amount of information given

How satisfied were you with the **clarity** of the information given to you by your health care professional(s)?

	1	2	3	4	5	6	7	
Highly dissatisfied with the clarity of information given	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Highly satisfied with the clarity of information given

How satisfied were you with the **accuracy** of the information given to you by your health care professional(s)?

	1	2	3	4	5	6	7	
Highly dissatisfied with the accuracy of information given	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Highly satisfied with the accuracy of information given

End of Block: Block 8

Start of Block: Block 12

Did you seek out or research additional information about the whooping cough vaccine or whooping cough as a disease to help you make your decision? This could be from searching on the internet, talking to a friend or family, reading pregnancy books, talking to other health professionals or anything else that would have aided you in your decision

- ☐ Yes
- ☐ No
- ☐ Can't remember

Skip To: End of Block If answer!= Yes

Display This Question:

If answer = Yes

If yes, where did you go for this additional information? Highlight all that apply

- ☐ The internet (articles and news) e.g. NHS Choice, Net doctor
- ☐ The internet (forums and discussion with other women) e.g. Mumsnet, Netmums, Facebook, Twitter
- ☐ Another NHS health care professional
- ☐ A private health care professional
- ☐ A complementary/alternative health care professional
- ☐ Friends and family members
- ☐ Parenting and pregnancy books and magazines
- ☐ e-books such as those purchased through google play or kindle
- ☐ Religious leaders
- ☐ Other

If any of these were sought could you please expand and give additional details in the box below.
E.g. which books, which internet sites.

Approximately how much effort did you put into searching for this additional information?

	1	2	3	4	5	
Not much effort, a casual search	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	A lot of effort, extensive searching

	Hours	Minutes
During your pregnancy, approximately how long (if at all) did you spend talking to friends and family members about the whooping cough vaccine?		

Do you feel that in total this influenced your decision?

- ☐ Yes greatly influenced
- ☐ Yes slightly influenced
- ☐ No influence

Display This Question:

If Do you feel that in total this influenced your decision? = Yes greatly influenced

Or Do you feel that in total this influenced your decision? = Yes slightly influenced

- ☐ Towards vaccination
- ☐ Away from vaccination

	Hours	Minutes
During your pregnancy, approximately how long (if at all) did you spend looking for information about the whooping cough vaccine on the internet?		

Do you feel that in total this influenced your decision?

- ☐ Yes greatly influenced
- ☐ Yes slightly influenced
- ☐ No influence

Display This Question:

If Do you feel that in total this influenced your decision? = Yes greatly influenced

Or Do you feel that in total this influenced your decision? = Yes slightly influenced

- ☐ Towards vaccination
- ☐ Away from vaccination

	Hours	Minutes
During your pregnancy, approximately how long (if at all) did you spend talking to health care professionals (not accounted for in the previous friends and family members question) about the whooping cough vaccine?		

Do you feel that in total this influenced your decision?

- ☐ Yes greatly influenced
- ☐ Yes slightly influenced
- ☐ No influence

Display This Question:

If Do you feel that in total this influenced your decision? = Yes greatly influenced
Or Do you feel that in total this influenced your decision? = Yes slightly influenced

Towards vaccination

- ☐ Away from vaccination

End of Block: Block 12

Start of Block: Debriefing

Study Debriefing

Thank you so much for completing this survey!

The study that you have just participated in focuses on if (and how) you gathered information about the whooping cough vaccination currently recommended to be taken during pregnancy.

People differ when it comes to making health care decisions, some people like to put complete responsibility for a decision onto their health care professional whereas others like to be deeply involved in the decision making process and conduct their own search for information before a decision is made. Many more people fall on a spectrum in-between these two extremes by placing

trust in a health care professional's advice while spending a little while checking the opinions of others.

The relationship with your health care professional and the way that you deal with stress may influence this.

Searching for information and being involved in a health care decision can often be very beneficial to health outcomes however occasionally this searching can lead to people making

their decision based on information from unreliable sources. This study intends to investigate this idea further.

How was this studied?

Over the course of the study you filled out the following scales and measures:

The Forest Wake Scale of Physician Trust

The Health Care Mistrust Scale

The Coping Strategy Inventory (short form)

An attitude to information seeking scale

A risk perception of vaccination during pregnancy scale

A satisfaction with information scale

These scales were combined with various single questions specific to this study.

Your answers from these questions will be combined with the answers of around 300 other women who have given birth within the past 6 months (recent enough that hopefully you all still remember decisions that you made during your pregnancy and how you went about making them). This data will be subjected to a number of statistical tests which will be able to give us a good idea of how women feel about the whooping cough vaccine and whether more needs to be done to effectively communicate its importance and effectiveness.

Additional details

This study forms part of a wider PhD research project conducted by the primary investigator Mr Richard Clarke (LSHTM; email: Richard.clarke@lshtm.ac.uk). The PhD is funded by the Economic and Social Research Council (ESRC) and supervised by Dr Pauline Paterson (LSHTM; email:

Pauline.paterson@lshtm.ac.uk) and Dr Miroslav Sirota (University of Essex; email: msirota@essex.ac.uk)

Additional feedback

Below is a text box. If you would like to give any additional feedback about either your experiences with vaccinations during pregnancy, your experiences in completing this survey, or your thoughts about this project we would like to hear them.

Continue to the next page for entry into the Prize draw



Feedback and any extra comments about the whooping cough vaccine

As a thank you for participating in this research project we are running a prize draw to win one of three gift vouchers (2 x £50, 1 x £100) of your choice (Mothercare or Amazon). To enter please enter your e-mail address into the box below

Note the following in accordance with ethical research practice:

This e-mail address:

1. Will not be linked to any of the data that you have just given.
2. Will not be given or sold to any third party.
3. Will be deleted after the prize draw has been conducted.
4. Will not be used to contact you about any further research conducted by the investigator or the London School of Hygiene & Tropical Medicine.
5. Will only be used as a means of contacting you if you win the prize draw.
6. After inputting your e-mail address click next to submit your responses

Thank you

I'm afraid that due to the inclusion criteria you are not eligible to take part in this survey. This study requires that you:

1. Have given birth during the last 6 months as of receiving this survey
2. Have spent the majority of your pregnancy in England or Wales
3. Describe your level of English as fluent

If **all of these** criteria do apply to you then there is a chance that you selected the wrong option. If that is the case feel free to click the link and start again.

If you are not eligible to take part in this study maybe you know someone that is

If you know someone who may be eligible to take part in this survey please send them the link to the survey. This will really help us make the results of this survey as meaningful as possible.

If you have any questions about this project please feel free to contact the lead investigator Mr Richard Clarke on Richard.Clarke@lshtm.ac.uk or either of the additional investigators Dr Pauline Paterson (Pauline.paterson@lshtm.ac.uk) or Dr Miroslav Sirota (msirota@essex.ac.uk).

Appendix F: Questionnaire 2 (part 1 and 2)

Your pregnancy and vaccination

PRIMARY INVESTIGATOR

Mr Richard Clarke Bsc, Msc, MPhil (The London School of Hygiene & Tropical Medicine)

ADDITIONAL INVESTIGATORS

Dr Pauline Paterson (The London School of Hygiene & Tropical Medicine), Dr Miroslav Sirota (The University of Essex)

INVITATION

You are invited to take part in a research study related to your views and experiences during your current pregnancy. Specifically the research is related to the whooping cough vaccination that you will soon be offered by your primary health care professional. You are eligible to take part in this research if you are currently between 4 and 17 weeks pregnant, you are fluent in English and you currently live in England or Wales and plan on remaining for the majority of your pregnancy.

This project has received ethical approval [LSHTM ethics REF: 13898] and forms part of a set of studies being conducted for a PhD research project based at The London School of Hygiene & Tropical Medicine.

WHAT WILL HAPPEN

This study will involve you being contacted and asked to fill out a survey at two different time points (one of these being now). The first survey involves filling out a few basic questions and then reading the official NHS information about the whooping cough vaccine currently recommended to be taken

during pregnancy. At the end of this you will be asked to provide your e-mail address. This will be used to contact you nearer the end of your pregnancy for follow up questions.

TIME COMMITMENT

Each of the two surveys are likely to take around 10-15 minutes to complete.

COMPENSATION

To compensate you for your time and effort at the end of **each** survey you have the opportunity to be entered into a prize draw to win one of three gift vouchers (2 x £50, 1 x £100) of your choice (Mothercare or Amazon). Therefore if you complete both surveys you are entered into the prize draw twice.

If you would like to participate in the survey please continue to the next page where you will be informed of details relating to confidentiality and anonymity related to the responses that you give during the course of completing this questionnaire.

End of Block: Intro and consent

Start of Block: Participant consent

Participant consent

PARTICIPANTS' RIGHTS

Participation in this research study is completely voluntary. Even after you agree to participate and begin the study you are still free to withdraw at any time and without having to give a reason. Only the recorded data from respondents that complete the full survey will be used in later analysis.

If, for any reason, you would like to withdraw your data from the study after you have completed the questionnaire you can contact the primary investigator (Richard.clarke@lshtm.ac.uk) anytime during the run of the project and the data will be removed from any analyses.

DATA STORAGE AND FUTURE USE

The data we collect for research purposes shall not contain any personal information about you, other than your age, ethnicity and the first part of your postcode. No one will link the data you provide to the identifying information you supply (e.g., your name or e-mail address).

All data will be stored securely at The London School of Hygiene and Tropical medicine. This data will be published in aggregate and may be shared publically with the intent to aid related research. In the case of this anonymity of will be assured through the removal of potentially identifiable information.

RISKS/DISCOMFORT

There are no known risks for you in this study however a few of the questions may be of a personal nature. If you do experience any stress or discomfort as a result of the issues raised here it is recommend that you discuss these feelings with a close friend or relative and if feelings of distress continue to contact your GP or local counselling service

FOR FURTHER INFORMATION

If you have any additional questions/comments about this project please feel free to contact me (Richard Clarke) at any time and I will be happy to answer your questions. You can reach me on: richard.clarke@lshtm.ac.uk

This contact e-mail (and those of the other investigators) are included at the end of the survey.



In order to continue please read and consent to the following:

	Tick to consent
I have read and understood the above information and have no further questions regarding my participation in this study:	<input type="checkbox"/>
I understand that my participation is voluntary, and I am free to withdraw from the survey at any time without any obligation to explain my reasons for doing so:	<input type="checkbox"/>
I agree to the data I provide being analysed and published anonymously:	<input type="checkbox"/>

End of Block: Participant consent

Start of Block: Screening

Thank you for agreeing to participate in this research. First we would like to ask a few general questions about you. Due to the inclusion criteria of the study for some of you this survey may end after this page.

	Yes	No
Are you currently between 4 and 17 weeks pregnant?	<input type="radio"/>	<input type="radio"/>
Do you currently live in either England or Wales?	<input type="radio"/>	<input type="radio"/>
Would you describe your level of English as fluent?	<input type="radio"/>	<input type="radio"/>

End of Block: Screening

Start of Block: Demographics



Age in Years



First part of your postcode (e.g. CM9 or NW10)

Which ethnic group do you belong to

- ☐ White:- British
- ☐ White:- Irish
- ☐ White:- Other white background
- ☐ Mixed:- White and Black Caribbean
- ☐ Mixed:- White and Black African
- ☐ Mixed:- White and Asian
- ☐ Mixed:- Other mixed background
- ☐ Asian or Asian British:- Indian
- ☐ Asian or Asian British:- Pakistani
- ☐ Asian or Asian British:- Bangladeshi
- ☐ Asian or Asian British:- Other Asian background
- ☐ Chinese
- ☐ Other ethnic group not represented by these options
- ☐ Do not wish to say

How many pregnancies have you had that have entered or passed the 3rd trimester (week 29 – 40)? _____

Currently, how many weeks pregnant are you? _____

End of Block: Demographics

Start of Block: Vaccine Hesitancy

Over the next couple of pages we would like to ask you for some information about how you feel about vaccinations in general and how you feel about vaccination during pregnancy specifically (there are no right or wrong answers here, we are looking for your honest views on the subject).

For the following questions please select you level of agreement/disagreement for each statement using the key provided.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
Childhood vaccines are (or will be) important for my child's health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Childhood vaccines are effective.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having my child vaccinated is important for the health of others in my community.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All childhood vaccines offered by the government program in my community are beneficial.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New vaccines carry more risks than older vaccines.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The information I receive about vaccines from the health care system is reliable and trustworthy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting vaccines is a good way to protect my child/children from disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Generally I do (or plan to do) what my doctor or health care professional recommends about vaccines for my child/children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am concerned about serious adverse effects of vaccines.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child/children will not need vaccines for diseases that are not common anymore.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Vaccine Hesitancy

Start of Block: Aware

The following questions refer to the whooping cough (also known as pertussis) vaccine that is often given to pregnant women between weeks 18 and 36 of pregnancy.

Before starting this survey were you aware (or at least partially aware) that it is currently recommended that all pregnant women receive the whooping cough vaccine during pregnancy?

- ☐ Yes
- ☐ No
- ☐ Not sure

End of Block: Aware

Start of Block: Vaccine during pregnancy risk perception

In general, I am...

- ☐ Absolutely against vaccination during pregnancy
 - ☐ Strongly against vaccination during pregnancy
 - ☐ Somewhat against vaccination during pregnancy
 - ☐ Neutral regarding vaccination during pregnancy
 - ☐ Somewhat in favour of vaccination during pregnancy
 - ☐ Strongly in favour of vaccination during pregnancy
 - ☐ Absolutely in favour of vaccination during pregnancy
-

The benefits of **vaccinating against whooping cough** during pregnancy outweigh the risks

- ☐ Strongly disagree
 - ☐ Disagree
 - ☐ Neither agree or disagree
 - ☐ Agree
 - ☐ Strongly Agree
-

Whooping cough (as a disease) is common in my area among babies and children.

- ☐ Strongly disagree
 - ☐ Disagree
 - ☐ Neither agree or disagree
 - ☐ Agree
 - ☐ Strongly Agree
-

Whooping cough (as a disease) is common in my area among adults.

- ☐ Strongly disagree
 - ☐ Disagree
 - ☐ Neither agree or disagree
 - ☐ Agree
 - ☐ Strongly Agree
-

Whooping cough (as a disease) can cause severe health issues...

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
for an unborn baby.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
for a baby or child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
for a pregnant women.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
for a non-pregnant adult.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

When given during pregnancy, side effects caused by **the whooping cough vaccine** can cause severe health issues for the pregnant women.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree or disagree
- ☐ Agree
- ☐ Strongly Agree

When given during pregnancy, side effects caused by **the whooping cough vaccine** can cause severe health issues for the unborn baby.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree or disagree
- ☐ Agree
- ☐ Strongly Agree
-

Side effects from **the whooping cough vaccine** during pregnancy are likely...

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
for an unborn baby.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
for a pregnant woman.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Vaccine during pregnancy risk perception

Start of Block: Block 12

It is likely that you will soon be prompted by your Midwife or GP to make a decision about the whooping cough vaccine for your own current pregnancy.

On the next three pages you will see the information from a leaflet that a lot of women currently see prior to making their decision to vaccinate for whooping cough during their pregnancy.

Please read through at your own pace, paying close attention to the factual details that the information contains.

End of Block: Block 12

Whooping cough (Pertussis)

What is whooping cough?

Whooping cough is a highly infectious disease that can be very serious for babies under one year of age. Most young babies with whooping cough will be admitted to hospital.

Whooping cough can cause long bursts of coughing and choking making it hard to breathe. The 'whoop' noise is caused by gasping for breath after each burst of coughing. Young babies don't always make this sound so it can be difficult to recognise.

Whooping cough commonly lasts for around two to three months. For young babies it can lead to pneumonia and permanent brain damage. In the worst cases, it can cause death.

Around 300 babies are admitted to hospital every year with whooping cough. Other complications of the infection include:

- temporary pauses in breathing as a result of severe difficulty with breathing
- weight loss due to excessive vomiting
- seizures or brain damage
- encephalitis (swelling of the brain)

Why do I need the whooping cough vaccine?

In 2012 there was an increase in the number of people getting whooping cough in the UK, 400 of these were babies under three months of age and of these 14 babies died.

To help prevent more deaths, a whooping cough vaccination programme for pregnant women started during 2012. You will be offered the whooping cough vaccine by your GP or maternity services from your 18th week of pregnancy. Your body will produce antibodies to whooping cough which are passed through the placenta to your baby. Your baby then has some protection against whooping cough when it is born. This protection will wear off and your baby should have their whooping cough vaccine at 8 weeks of age.

Please tick to confirm that you have read the above text []

Page Break

When should I get vaccinated?

The best time to get vaccinated to protect your baby is from the 18th week of your pregnancy or soon after your 20 week scan. If you miss the recommended time you can have the vaccine any time in your pregnancy. The vaccine is a single injection in your arm.

Because protection from whooping cough vaccine wears off over time, you should have the vaccine even if you had it when you were younger or if you have had whooping cough. You should also have it again, if you had it in a previous pregnancy, as vaccination is needed in each pregnancy.

The whooping cough vaccine can be given at the same time as the flu vaccine but do not wait until the winter season to have them together. Your baby will get the best protection if you have the vaccine from the 18th week of your pregnancy.

If you haven't heard from your GP or midwife, then make an appointment to have the vaccination at your earliest opportunity.

I thought babies were given the whooping cough vaccine?

In the UK, babies are given the whooping cough vaccine at 8, 12 and 16 weeks of age. They are not given their whooping cough vaccines earlier than 8 weeks as they may not respond as well. Babies need three doses of the vaccine to build up full protection.

You can help to protect your new-born baby by having the whooping cough vaccine soon after the 18th week of your pregnancy.

What are the benefits for my baby?

The only way to protect your baby from getting whooping cough in the first two months of life is by having the whooping cough vaccine yourself. The protection that you will get from the vaccine passes to your baby through the placenta and protects your baby from whooping cough until they are old enough to have their own vaccine. Studies have shown that the vaccine is very effective in preventing whooping cough in new-born babies. The protection that you will get from the vaccination also means that you are less likely to catch whooping cough and pass it on to your baby.

Please tick to confirm that you have read the above text []

Is the whooping cough vaccine safe to have during pregnancy?

Studies have shown the whooping cough vaccine is very safe for you and your baby. You may have some of the common mild side effects. These include: swelling, redness and tenderness at the injection site.

The vaccine will also boost your protection against tetanus, polio and diphtheria.

It is much safer for you and your baby to have the vaccine than to risk your new-born catching whooping cough.

Whooping cough can be a very serious illness for young babies. You can help to protect your baby by having the vaccine from the 18th week of your pregnancy.

Remember, even if you've had whooping cough vaccine while pregnant, the protection that this will give to your baby will wear off so it is important that your baby has their own vaccines at 8, 12 and 16 weeks of age.

Please tick to confirm that you have read the above text []

End of Block: Information about WC vaccine

Start of Block: Block 10

The following questions are intended to gain an understanding of how satisfied/dissatisfied you are with the information you were previously presented with.

How satisfied were you with the **amount** of the information?

	1	2	3	4	5	6	7	
Highly dissatisfied with the amount of information given	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Highly satisfied with the amount of information given

How satisfied were you with the **depth** of the information?

	1	2	3	4	5	6	7	
Highly dissatisfied with the depth of information given	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Highly satisfied with the depth of information given

How satisfied were you with the **clarity** of the information?

	1	2	3	4	5	6	7	
Highly dissatisfied with the clarity of information given	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Highly satisfied with the clarity of information given

After reading this information were there any questions you had about the whooping cough vaccination program that you feel **were not** adequately answered by the information presented

- ☐ Yes
- ☐ No
- ☐ Unsure

If yes please note the questions you would have liked to have seen answered in the box below.

End of Block: Block 10

Start of Block: Decision conflict

Thinking about the choice you will soon be required to make (to vaccinate for whooping cough during pregnancy or not), please look at the following comments commonly made by some people when making a similar decision. Please indicate, by selecting from strongly agree to strongly disagree, how you feel about the choice you are about to make.

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
This decision is hard for me to make	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm unsure what to do in this decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It's clear what choice is best for me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm aware of the choices I have to protect myself and my baby from whooping cough	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I know the benefits of the whooping cough vaccination given during pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel I know the risk and side effects of the whooping cough vaccination given during pregnancy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I need more advice and information about the choices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know how important the benefits of the whooping cough vaccination given during pregnancy are to me in this decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know how important the risks and side effects of the whooping cough vaccination given during pregnancy are to me in this decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It's hard to decide if the benefits are more important to me than the risks, or if the risks are more important than the benefits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel pressure from others in making this decision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have the right amount of support from others in making this choice	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate how strongly you either agree or disagree with the following statement: I intend to vaccinate for whooping cough during my current pregnancy

	1	2	3	4	5	6	7	
Strongly disagree	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Strongly agree

End of Block: Decision conflict

Start of Block: Debriefing part 1 Main

Thank you for completing part one of this study

As mentioned during the introduction this study is in two parts. To be contacted to take part in the second part of this study, and to enter into the prize draw to win one of three gift vouchers (2 x £50, 1 x £100) of your choice (Mothercare or Amazon), please enter your e-mail address and phone number into the boxes below.

E-mail address: _____

Phone number: _____

Note the following in accordance with ethical research practice. These details:

- Will not be linked to any of the data that you have just given.
- Will not be given or sold to any third party.
- Will be deleted after the prize draw has been conducted.
- Will not be used to contact you about any further research conducted by the investigator or the London School of Hygiene & Tropical Medicine.
- Will only be used as a means of contacting you for the subsequent survey and if you win the prize draw. Contact by phone will only be through text message.

After inputting your e-mail address click next to submit your responses.

If you would like to withdraw from the study at this point please e-mail the lead investigator Richard.clarke@lshtm.ac.uk to receive the full debriefing for this study.

End of Block: Debriefing Main

Start of Block: Ask of participants

Help us make the results of this project as meaningful as possible

Thank you that's all we need from you for now, we hope to hear from you again when we contact you nearer the end of your pregnancy.

In the meantime however there is a good chance that you will soon be meeting (or currently know) other mothers at a similar stage of pregnancy. If you know of someone who may be eligible to take part in this survey and think that they would like to help please either send them the below link directly, Share with them the top "pinned" post on the projects Facebook page [here](#) or point them in the direction of my website [here](#).

The more people that take this survey the more meaningful the results become. Our current aim for this project is to hear from at least 150 women that are between 4 and 17 weeks of pregnancy so any help you can give would be very much appreciated!



E-S-R-C
ECONOMIC & SOCIAL
RESEARCH
COUNCIL



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SCHOOL of
HYGIENE
& TROPICAL
MEDICINE

Are you currently between 4 and 17 weeks pregnant?

If so, researchers from The London School of Hygiene & Tropical Medicine are keen to hear from you.

We are conducting a survey-based research study into communication and risk based decision making across pregnancy.

If you are willing to complete a simple survey now and another after 36 weeks of pregnancy to help with this research please follow the link posted with this message or visit www.richardclarkeresearch.com for further details.

By participating in this research you will have the opportunity to enter into a prize draw to win your choice of a Mothercare or Amazon voucher worth either **£50** (2 available to win) or **£100** (1 available to win).



Link to this study: https://essex.eu.qualtrics.com/jfe/form/SV_9uy1eBFc0cycrZz

Many thanks,

Richard

Mr Richard Clarke PhD candidate Infectious Disease Epidemiology Department Faculty of Epidemiology & Population Health London School of Hygiene & Tropical Medicine Keppel Street London WC1E 7HT

End of Block: Ask of participants

Start of Block: No eligible debriefing

I'm afraid that due to the inclusion criteria you are not eligible to take part in this survey. This study requires that you:

1. Currently are between 4 and 17 weeks of pregnancy
2. Currently live in England or Wales
3. Describe your level of English as fluent

If **all of these** criteria do apply to you then there is a chance that you selected the wrong option. If that is the case feel free to click the link and start again.

If you are not eligible to take part in this study do you know someone that is?

If you know someone who may be eligible to take part in this survey please send them the link to the survey. This will really help us make the results of this survey as meaningful as possible.

If you have any questions about this project please feel free to contact the lead investigator Mr Richard Clarke on Richard.Clarke@lshtm.ac.uk or either of the additional investigators Dr Pauline Paterson (Pauline.paterson@lshtm.ac.uk) or Dr Miroslav Sirota (msirota@essex.ac.uk).

End of Block: No eligible debriefing

Your pregnancy and vaccination (part 2)

Welcome back to the study. To refresh your memory, below is some of the basic information about the study and your rights as a participant within the study.

PRIMARY INVESTIGATOR

Mr Richard Clarke Bsc, Msc, MPhil (The London School of Hygiene & Tropical Medicine).

ADDITIONAL INVESTIGATORS

Dr Pauline Paterson (The London School of Hygiene & Tropical Medicine), Dr Miroslav Sirota (The University of Essex).

ETHICAL APPROVAL

This project has received ethical approval [LSHTM ethics REF: 13898] and forms part of a set of studies being conducted for a PhD research project based at The London School of Hygiene & Tropical Medicine.

WHAT WILL HAPPEN

The following is the second in a two part survey study. Last time you may remember that you were shown some information about the whooping cough vaccine given during pregnancy. At this time we

would like to ask some similar questions as last time and also some questions about how you finally came to a decision related to the whooping cough vaccine.

At the end of this survey you will again be entered into a prize draw to win one of three available gift vouchers worth £50-£100.

TIME COMMITMENT

This survey will take around 10 minutes to complete.

If you would like to participate in the survey please continue to the next page where you will be informed of details relating to confidentiality and anonymity related to the responses that you give during the course of completing this questionnaire.

Please enter your e-mail address (if you have multiple please make sure it is the addresses you received the link to this survey from) so that we can link your responses here with those of your first survey:

Participant consent

PARTICIPANTS' RIGHTS

Participation in this research study is completely voluntary. Even after you agree to participate and begin the study, you are still free to withdraw at any time and without having to give a reason. Only the data from respondents that complete the full survey will be used in later analysis.

If, for any reason, you would like to withdraw your data from the study after you have completed the questionnaire you can contact the primary investigator (Richard.clarke@lshtm.ac.uk) anytime within two weeks of completion and the data will be removed from any analyses.

DATA STORAGE AND FUTURE USE

The data we collect for research purposes shall not contain any personal information about you, other than your age, ethnicity and the first part of your postcode. No one will link the data you provide to the identifying information you supply (e.g., your name or e-mail address).

All data will be stored securely at The London School of Hygiene & Tropical Medicine. This data will be published in aggregate and may be shared publically with the intent to aid related research and public health communication. In the case of this anonymity will be assured through the removal of potentially identifiable information.

RISKS/DISCOMFORT

There are no known risks for you in taking part in this study however a few of the questions may be of a personal nature. If you do experience any stress or discomfort as a result of the issues raised

here it is recommended that you discuss these issues with a close friend or relative and if feelings of distress continue to contact your GP or local counselling service

FOR FURTHER INFORMATION

If you have any additional questions/comments feel free to contact me (Richard Clarke) at any time and I will be happy to answer your questions. You can reach me on: Richard.clarke@lshtm.ac.uk

This contact e-mail (and those of the other investigators) and a full explanation of the reason for this study are included at the end of the survey.

In order to continue please read and consent to the following:

	Tick to consent
I have read and understood the above information and have no further questions regarding my participation in this study:	<input type="checkbox"/>
I understand that my participation is voluntary, and I am free to withdraw from the survey at any time without any obligation to explain my reasons for doing so:	<input type="checkbox"/>
I agree to the data I provide being analysed and published anonymously:	<input type="checkbox"/>

End of Block: Consent

Start of Block: Vaccine hesitancy

Over the next couple of pages we would now like to ask you for some information about how you feel about vaccinations in general and how you feel about vaccination during pregnancy specifically (there are no right or wrong answers here, we are looking for your honest views on the subject).

For the following questions please select your level of agreement/disagreement for each statement using the key provided.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
Childhood vaccines are important for my child's health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Childhood vaccines are effective.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having my child vaccinated is important for the health of others in my community.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
All childhood vaccines offered by the government program in my community are beneficial.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
New vaccines carry more risks than older vaccines.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The information I receive about vaccines from the health care system is reliable and trustworthy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting vaccines is a good way to protect my child/children from disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Generally I do (or plan to do) what my doctor or health care professional recommends about vaccines for my child/children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am concerned about serious adverse effects of vaccines.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My child/children will not need vaccines for diseases that are not common anymore.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Vaccine hesitancy

Start of Block: Risk perception

In general, I am...

- ☐ Absolutely against vaccination during pregnancy
- ☐ Strongly against vaccination during pregnancy
- ☐ Somewhat against vaccination during pregnancy
- ☐ Neutral regarding vaccination during pregnancy
- ☐ Somewhat in favour of vaccination during pregnancy
- ☐ Strongly in favour of vaccination during pregnancy
- ☐ Absolutely in favour of vaccination during pregnancy

The benefits of **vaccinating against whooping cough** during pregnancy outweigh the risks

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree or disagree
- ☐ Agree
- ☐ Strongly Agree

Whooping cough (as a disease) is common in my area among babies and children.

- ☐ Strongly disagree
 - ☐ Disagree
 - ☐ Neither agree or disagree
 - ☐ Agree
 - ☐ Strongly Agree
-

Whooping cough (as a disease) is common in my area among adults.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree or disagree
- ☐ Agree
- ☐ Strongly Agree
-

Whooping cough (as a disease) can cause severe health issues...

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
for an unborn baby.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
for a baby or child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
for a pregnant women.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
for a non-pregnant adult.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

When given during pregnancy, side effects caused by **the whooping cough vaccine** can cause severe health issues for the pregnant women.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree or disagree
- ☐ Agree
- ☐ Strongly Agree

When given during pregnancy, side effects caused by **the whooping cough vaccine** can cause severe health issues for the unborn baby.

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree or disagree
- ☐ Agree
- ☐ Strongly Agree

Side effects from **the whooping cough vaccine** during pregnancy are likely...

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
for an unborn baby.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
for a pregnant woman.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: Risk perception

Start of Block: Encouragement

Were you encouraged to vaccinate against whooping cough by a health care professional during your pregnancy?

- ☐ Yes
- ☐ No
- ☐ Cannot remember

Display This Question:

If answer = Yes

How strongly did your health care professional recommend that you get the whooping cough vaccine during your pregnancy? Please rate somewhere on the 7 points given below

	1	2	3	4	5	6	7	
Health care professional recommended it in passing but appeared to give little importance to it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	Health care professional strongly recommended the vaccine and gave great importance to it

During your pregnancy did you receive the whooping cough vaccine?

- ☐ Yes
- ☐ No
- ☐ Cannot remember

Display This Question:

If answer = Yes

Did you experience any side effects due to the whooping cough vaccine?

- ☐ Yes
- ☐ No
- ☐ Cannot remember

Display This Question:

If During your pregnancy did you receive the whooping cough vaccine? = Yes

If you would like to leave any additional information in relation to this question please feel free to use the text box below

End of Block: Encouragement

Start of Block: Vaccine information seeking behaviour questions

Did you actively seek out additional information about the whooping cough vaccine or whooping cough as a disease to help you make your decision? (This includes talking to a friend or family member about the vaccine, searching the internet, reading pregnancy books or magazine articles about the vaccine, etc)

- ☐ Yes
- ☐ No
- ☐ Can't remember

Since completing the previous survey (taken before 18 weeks of pregnancy) have you done any of the following, highlight all that apply. If none, please leave blank.

- ☐ Used the internet to read articles or news about the whooping cough vaccine given during pregnancy (e.g. NHS Choice, Net doctor, Patient.com).
- ☐ Used the internet to read comments or discussions from other women that have talked publicly on forums about the whooping cough vaccine (e.g. Mumsnet, Netmums, Facebook, Twitter etc).
- ☐ Actively brought up the topic of the whooping cough vaccine given during pregnancy with your GP, Midwife, health visitor or nurse practitioner.
- ☐ Actively brought up the topic of the whooping cough vaccine given during pregnancy with a complementary/alternative health care professional.
- ☐ Actively brought up the topic of the whooping cough vaccine given during pregnancy with a religious or spiritual leader.
- ☐ Actively brought up the topic of the whooping cough vaccine given during pregnancy with a friend or family member that has had past medical training.
- ☐ Actively brought up the topic of the whooping cough vaccine given during pregnancy with a friend or family member (not medically trained).
- ☐ Searched health care during pregnancy books or e-books for additional information on the whooping cough vaccine given during pregnancy.
- ☐ Other.

If any of these were sought could you please expand and give additional details in the box below.
E.g. Which books, which internet sites.

What, if any, was your main reason for seeking information from the sources such as those selected above?

Page Break

The following question refer to the amount of time you spent talking to people you know about the vaccine. Please select from the drop arrows approximately how many hours and minutes you spent for each question. If the answer is zero please select 0 from both the hours and minutes drop down lists in order to proceed.



	Hours	Minutes
During your pregnancy how long (if at all) did you spend talking to friends and family members about whooping cough or the whooping cough vaccine?	▼ 0 ... 10+	▼ 0 ... 55

Display This Question:

If time is > 0

Do you feel that, in total, talking to your friends and family influenced your intentions to vaccinate for whooping cough during your current pregnancy?

- ☐ Greatly away from vaccination
- ☐ Somewhat away from vaccination
- ☐ Slightly away from vaccination
- ☐ No influence
- ☐ Slightly towards vaccination
- ☐ Somewhat towards vaccination
- ☐ Greatly towards vaccination

The following question refer to the amount of time you spent looking for information about the vaccine on the internet. Please select from the drop arrows approximately how many hours and minutes you spent for each question. If the answer is zero please select 0 from both the hours and minutes drop down lists in order to proceed.



	Hours	Minutes
During your pregnancy how long (if at all) did you spend looking for information about whooping cough or the whooping cough vaccine on the internet?	▼ 0 ... 10+	▼ 0 ... 55

Display This Question:

If time is > 0

Do you feel that in total looking for information on the internet influenced your intentions to vaccinate for whooping cough during your current pregnancy?

- ☐ Greatly away from vaccination
- ☐ Somewhat away from vaccination
- ☐ Slightly away from vaccination
- ☐ No influence
- ☐ Slightly towards vaccination
- ☐ Somewhat towards vaccination
- ☐ Greatly towards vaccination

The following question refer to the amount of time you spent talking to health care professionals about the vaccine. Please select from the drop arrows approximately how many hours and minutes you spent for each question. If the answer is zero please select 0 from both the hours and minutes drop down lists in order to proceed.



	Hours	Minutes
During your pregnancy how long (if at all) did you spend talking to health care professionals (not accounted for in the previous friends and family members question) about whooping cough or the whooping cough vaccine?	▼ 0 ... 10+	▼ 0 ... 55

Display This Question:

If time is > 0

Do you feel that in total talking to a health care professional influenced your intentions to vaccinate for whooping cough during your current pregnancy?

- ☐ Greatly away from vaccination
- ☐ Somewhat away from vaccination
- ☐ Slightly away from vaccination
- ☐ No influence
- ☐ Slightly towards vaccination
- ☐ Somewhat towards vaccination
- ☐ Greatly towards vaccination

End of Block: Vaccine information seeking behaviour questions

Start of Block: Block 6

Study Debriefing

Thank you for completing part two of this study. You will now be entered again into the prize draw to win one of three gift vouchers (2 x £50, 1 x £100) of your choice (Mothercare or Amazon).

The study that you have just participated in focused on if (and how) you gathered information about the whooping cough vaccination in order to aid in the decision making process.

Searching for information and being more involved in a health care decision can often be very beneficial to health outcomes. However occasionally searching for additional information can lead to sources of information that are unreliable or bias. This study intends to investigate the factors that are involved in information seeking behaviour and the impact it has on a vaccination decision.

The information you received during the first part of this study was taken verbatim from the leaflet:

Pregnant? There are many ways to help protect you and your baby (PHE 2016)

Which is available to find online, or by e-mailing the primary investigator, if you wish to view it again.

Over the course of the study you filled out the following scales and measures:

- The vaccine hesitancy scale
- A risk perception of vaccination during pregnancy scale
- A decision conflict scale

The first two of these scales were asked twice so as to see if any change occurred during your pregnancy. This will be compared to the answers related to where and how long you spent researching the vaccine, the recommendation from your health care professional and whether or not you took the vaccine.

Your answers from these questions will be combined with the answers of around 200 other women who are currently at the same period of their pregnancy. This data will be subjected to a number of statistical tests which will be able to give us a good idea of how women interact with the information

that is given out as standard practice and what may be preferred or missing in the current communication strategy.

Additional details

This study forms part of a wider PhD research project conducted by the primary investigator Mr Richard Clarke (LSHTM; email: Richard.clarke@lshtm.ac.uk). The PhD is funded by the Economic and Social Research Council (ESRC) and supervised by Dr Pauline Paterson (LSHTM; email: Pauline.paterson@lshtm.ac.uk) and Dr Miroslav Sirota (University of Essex; email: msirota@essex.ac.uk).

Additional feedback

Below is a text box. If you would like to give any additional feedback about either your experiences with vaccinations during pregnancy, your experiences in completing this survey, or your thoughts about this project we would like to hear them.

End of Block: Block 6

Appendix G: Sensitivity analyses associated with the analysis in chapter 5

To check the robustness of the findings included in chapter 5 a series of sensitivity analyses were conducted using the available demographic variables that are frequently mentioned as important in previous literature. These variables included age, ethnicity, week of pregnancy when contacted for Questionnaire T1 and number of previous pregnancies (parity).

Sensitivity analysis 1: Predicting vaccine information seeking behaviour (Hypothesis 1)

The variables significantly predicted the perceived strength and direction of influence of information found through seeking, $F(8,181) = 4.048$, $p < .001$, and successfully explained 11.9% of the variance (Adjusted $R^2 = 0.119$), .9% more variance than the original model. Number of previous pregnancies (parity) should be an indication of a confounding effect however when the Bonferroni adjustment is applied significance is lost. All variables that were previously significant in the model remain significant.

Variable	<i>B</i>	95% <i>CI</i>		<i>t</i>	<i>p</i>
		<i>Lower</i>	<i>Upper</i>		
Constant	3.188				
Risk perception of vaccination during pregnancy	.231	.089	.372	3.216	.002
Vaccine confidence	-.403	-.665	-.141	-.376	.003
Decision conflict	.053	-.142	.247	.534	.594
Intention to vaccinate	-.066	-.162	.029	-1.369	.173
Week of pregnancy at T1	-.003	-.028	.021	-.278	.781
Age	.001	-.024	.026	.096	.923
Parity	-.136	-.253	-.019	-2.292	.023
Ethnicity	.102	-.313	.518	.485	.628

Alpha was $p < .006$ as adjusted for multiple comparisons

Shading indicates the adjusting for the variables: Week of pregnancy at time one, years of age, parity (number of previous pregnancies) and ethnicity (binary variable white/other ethnicity selected).

Sensitivity analysis 2: Predicting the perceived influence of information (Hypothesis 2).

The variables significantly predicted the perceived strength and direction of influence of information found through seeking, $F(8,160) = 2.458$, $p \leq .016$, and successfully explained 6.8% of the variance (Adjusted $R^2 = 0.068$), .03% more variance than the original model. None of the additional variables predicted the perceived influence of information. Intention to vaccinate remains the only significant variable.

Variable	<i>B</i>	95% <i>CI</i>		<i>t</i>	<i>p</i>
		<i>Lower</i>	<i>Upper</i>		
Constant	-.579				
Risk perception of vaccination during pregnancy	.036	-.209	.282	.290	.772
Vaccine confidence	.039	-.440	.519	.163	.871
Decision conflict	.095	-.233	.422	.571	.569
Intention to vaccinate	.222	.048	.396	2.516	.013
Week of pregnancy at T1	.018	-.023	.06	.878	.381
Age	-.018	-.06	.024	-.847	.398
Parity	-.138	-.351	.074	-1.288	.351
Ethnicity	.277	-.427	.982	.778	.438

Sensitivity analysis 3: Predicting vaccine uptake (Hypothesis 3).

A total of 173 cases were analysed and the full model significantly predicted vaccine uptake (omnibus $\chi^2 = 56.830$, $df = 8$, $p < .001$). None of the additional variables were found to be significant in the model. Vaccine confidence remains the only significant variable, however caution should be used when interpreting this result due to its high p -value

Variable	<i>OR (Exp B)</i>	95% <i>CI</i>		<i>Wald</i>	<i>p</i>
		<i>Lower</i>	<i>Upper</i>		
Constant				5.551	.018

Risk perception of vaccination during pregnancy	1.082	.283	4.138	.013	.908
Vaccine confidence	11.14	1.219	101.96	4.558	.033
Vaccine information seeking behaviour (log)	1.637	.42	6.387	.504	.478
Intention to vaccinate	1.691	.871	3.28	2.412	.12
Strength of recommendation from healthcare professional	1.486	.849	2.602	1.922	.166
Age	1.077	.854	1.359	.395	.53
Parity	.863	.322	2.313	.085	.77
Ethnicity	3.649	.039	342.5	.312	.576

Sensitivity analysis 4: Predicting the change in risk perception of vaccination during pregnancy (Hypothesis 4).

As in the original model the variables did not predicted the change in risk perception that occurs between Questionnaire T1 and Questionnaire T2, $F(7,172) = 1.062$, $p = .391$ and none of the additional variables were significant in the model.

Variable	<i>B</i>	95% <i>CI</i>		<i>t</i>	<i>p</i>
		<i>Lower</i>	<i>Upper</i>		
Constant	.054				
Vaccine information seeking behaviour (log)	.053	-.086	.193	.756	.451
Vaccine Uptake	-.049	-.4	.302	-.275	.783
Strength of recommendation	-.041	-.106	.025	-1.234	.219
Week of pregnancy at T1	-.001	-.024	.22	-.049	.961
Age	-.011	-.035	.013	-.938	.349
Parity	.104	-.01	.218	1.803	.073
Ethnicity	.172	-.227	-.572	.851	.396